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Abstract

This dissertation explores the phenomena of how Registered Nurses in a New Zealand context participate in genetic conversations. The prominent themes identified in existing literature were; future orientated language and the idea of what nurses *will* need to know; the colonization of genetic counselling; and a paradigm shift called for by Dr. Gwen Anderson for nursing in genetics to move away from the biomedical approach to a holistic nursing model.

An identified gap in the literature related to no knowledge of how nurses engage in the topic of genetics- be it in a conversational space with patients or otherwise. A small focus group with registered nurses was conducted at a local hospital to explore this gap.

From the focus group four prominent themes emerged: senses of blame and responsibility; conversation content; the registered nurses role; and most prominently, feelings of being inadequately prepared, educated, or trained to meet the expected role. This dissertation calls for two primary actions; that the education and discussion of genetics move away from the borrowed biomedical model into an autonomous nursing space and that genetics be incorporated into nurse education at all levels. The FAMILY mnemonic has been developed to provide nurses with a tool to guide their genetic conversations.

Keywords: nursing, genetics, communication, FAMILY

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The last words though are for Mum and Dad; for their love and pride- no matter what.

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Glossary

Adrenoleukodystrophy: a serious progressive, genetic disorder that affects the adrenal glands, the spinal cord and the white matter of the nervous system

Allele: A variant form of a gene.

Allelic variation: Differences in gene expression between alleles.

ANA: American Nurses Association.

ATP: Adenosine triphosphate; the energy unit of a cell.

Autosome: A chromosome which is not a sex chromosome (sex chromosomes are called allosomes).

Carrier: Someone carrying a recessive allele for trait or mutation but does not display the trait nor are they symptomatic of the disease.

DNA fragmentation: When DNA strands have been broken or separated.

Dominant allele: Where the effect on phenotype is dominated by one allele which masks the influence of its corresponding allele.

Dominantly inherited disorder: Disorder that requires only one copy of the affected autosome to produce the disease/disorder phenotype.

Dysmorphism: Abnormality of form or structure

Gene: A region of DNA that codes for either a functional RNA or protein product. It is the transmission of genes which is the basis of inheritance of phenotypes.

Genetic conversations: any interaction in which [the nurse] responds to, initiates, communicates, or interacts in, situations where the concept, topic, or ideas about genetics arise

Genotype: Either, the individual's entire collection of genes, or, the two alleles at any locus inherited for a particular gene.

GP: General Practitioner

Guthrie test: A routine blood test carried out on babies a few days after birth to detect metabolic conditions.

IL28B: the name of a specific gene involved in the immune response to some viruses; including hepatitis C.

Mitochondria: An organelle of the cell in which respiration and energy production occurs.

Mutation: A permanent change in the nucleotide sequence of the genome (a mistake in the code).

OPD2: Otopalatodigital syndrome allelic variation 2 (type 2).

Otopalatodigital syndrome: an inherited disease linked to the X chromosome.

Paternal inheritance: Inherited from the father

PDRP: Professional development and recognition program.

Pharmacogenetics: inherited genetic differences in drug metabolic pathways.

Phenotype: the physical traits produced by the genotype.

Polymorphism: When there is more than one allele possible.

Reactive oxygen species: Chemically reactive molecules which contain oxygen. Also known as ROS; they are a byproduct of normal metabolism of oxygen.

X chromosome: A sex chromosome. Normally females have two copies and males have one.

X linkage: the phenotype result is related to the genotype carried by the X chromosome which influences its inheritance pattern (see X chromosome above).

Zebrafish: (Danio rerio): A model organism (a tropical freshwater fish) used for studies of vertebrate development.

CHAPTER ONE: BACKGROUND TO THE RESEARCH TOPIC

Origins

The purpose of this research is to explore how New Zealand nurses participate in genetic conversations. The importance of recognizing the nurse as a fundamental source of genetic information, or misinformation, has been highlighted by a 2010 study which demonstrated that patients regard genetic advice as equally valuable regardless of whether the source is an expert nurse or a physician (Barnoy, Levy, & Bar Tal, 2010).

An anecdotal experience observed by myself while a nursing student in practice, highlighted an unexplored phenomena; how do nurses talk to patients, or even each other, about genetic ideas or concepts? And is what they say true, or even helpful? Or do their answers leave people more anxious and vulnerable, or, relieved and empowered? Consider the following scenario:

> Miss N has learnt that her father has been diagnosed with Huntington's disease. On visiting him in hospital for an unrelated cardiac event she asks the nurse at the bedside what her father's diagnosis means for her.

The nurse has a range of options for her response. In this case, the nurse was observed telling Miss N that Huntington's is not passed from father to daughter and that her father had developed it due to his previous alcohol consumption.

This information was inaccurate. First identified in 1872, Huntington's disease is a dominantly inherited disorder with paternal inheritance often more severe than maternal (Lashley, 1998). This means the disease is passed to 50% of children from an affected person as illustrated in figure 1 below.

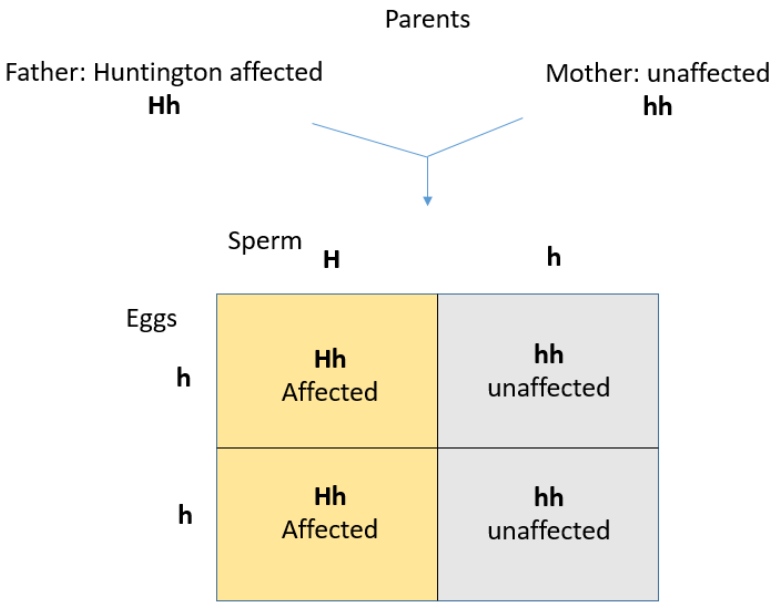


Figure 1: Punnett square demonstrating inheritance pattern of Huntington's disease from affected Father to next generation.

The severity comes from the nature of the mutation; Huntington's is caused by a repeating section that repeats more often than it should (U.S. National Library of Medicine, 2013). Inheriting the allele from the father often means more repeats than if it was inherited from an affected mother (Lashley, 1998). Symptoms often do not present until after age 35; by which time the affected individual has potentially had children of their own and passed the disease on (Campbell & Reece, 2008). This characteristic of the disease makes it commonly taught in biology as it demonstrates how a dominate allele which is lethal is maintained through generations. The symptoms of the disease, especially the slurred speech and unsteady gait, do get confused with alcoholism (Drapo, 1981; Wexler, 2010). In truth Miss N had a 50% chance of inheriting the disease from her father who either inherited the disease from a parent or less likely, developed the mutation independently.

Scenarios like this highlight the importance of exploring how the nurse at the bedside responds to genetic conversations. As a student a degree of powerlessness prevented me from

sharing the correct information. Confronting the misinformation in front of Miss N would have jeopardized the relationship the nurse had with her. Yet challenging the nurse in private would have placed myself in an awkward position as well as I was already identified as an unusual nursing student. I had a previous honors degree in genetics, reproduction and development and was undertaking the first dual degree program (Bachelor of Nursing and Master of Health Sciences) to nursing registration in New Zealand. As a student I was met with mixed reactions from nurses during my clinical practice hours. Some were excited for us as a class and others were unhappy, many voicing their concern- often regarding not doing the hard years of graft work as a nurse first before working towards a Masters. The fact it was a Masters of Health Sciences, not nursing, was often lost in translation. This made forming collegial relationships with nurses difficult at times and in the scenario above I instead discussed the event with my academic liaison nurse and no further action was taken.

My previous academic experience was predominately genetics focused and I spent my honors year investigating how increasing age affected spermatozoa quality. I was investigating aspects of motility, DNA fragmentation, levels of ATP and mitochondria and reactive oxygen species using Zebrafish as a model organism within the quantitative paradigm. The proximity of my research to fertility meant I also studied philosophy, politics and ethics in conjunction to become a conscientious researcher. Although I enjoyed research it was the human element I sought from a career and I was encouraged into nursing.

Sociopolitical context 1: Nurses and midwives

When initially discussing the research concept there were doubts from colleagues that the topic was relevant to nurses and perhaps was more appropriate for midwives. This idea was highlighted again when J. Westgarth, an individual who works closely with genetic testing and

results in the local hospital (personal communication, November 4, 2015), saw the recruiting drive for the project. She confirmed the relevancy of the topic for midwives but within her role, she had no contact with nurses.

New Zealand midwives work specifically with women and new born babies during pregnancy, labor and up to six-weeks postpartum and must met competencies to enter onto the Midwifery registry (Midwifery Council of New Zealand, 2015). Two of these competencies allude to genetic competence. Competency 2.2 states that the midwife orders relevant investigative and diagnostic tests and carries out necessary screening and 2.3 states the midwife must be able to recognize a condition which requires consultation or referral (Midwifery Council of New Zealand, 2007). There have been tensions between the professional body of registered midwives and other health professionals, particularly around the underlying philosophy and principles that differentiate midwifery from medicine (Abel, 1997). The Nurses Amendment Act 1990 allowed midwives to practice autonomously in pregnancies funded by the public health system which are not considered high risk (Sweetman, 2013). This Act created two distinct professions; nursing and midwifery (Kirkman, 2012). In line with this, competency 4.6 for midwifery registration states that midwives "direct, supervise, monitor and evaluate obstetric nursing care provided by registered obstetric nurses, enrolled nurses, registered general nurses or registered comprehensive nurses" (Midwifery Council of New Zealand, 2007, p. 5). This competency and the midwifery space created by the 1990 Amendment Act does not clarify the role the nurse nor the midwife plays when it comes to engaging in genetic conversations. A Canadian systematic review of the literature cited role ambiguity as a barrier to collaboration between nurses and midwives in providing birthing care (Macdonald, Campbell-Yeo, Snelgrove-Clarke, Aston, Helwig, & Baker, 2015). The ever growing body of literature suggests that genetics is a topic inherent in all aspects of health; not just for

newborns, which makes this research relevant to Registered Nurses in New Zealand (Westwood, Pickering, Latter, Lucassen, Little, & Temple, 2006).

Nurses Competencies

Internationally, competencies have set the expected standard for the skills, attitudes and knowledge for nurses regarding genetics (Beery & Workman, 2011; Genomics Policy Unit, 2003; Jenkins, Blitzer, Boehm, Feetham, Gettig, Johnson et al., 2001; Skirton, Lewis, Kent, & Coviello, 2010). In 2011 the American Nurses Association (ANA) published competencies for nurses at the masters or doctoral level stating they are at the interface of translating genetics and genomics into nursing care (Greco, 2011). The ANA also has stand-alone genetic and genomic competencies expected of all registered nurses regardless of academic preparation (American Nurses Association, 2009). These include being capable of obtaining and conveying genetic information to patients. Appendix 1 has the full set of competencies expected by the ANA and Appendix 2 has the competencies published by the Genomics Policy Unit of Wales.

Within New Zealand nursing education there is a level of competence expected at the graduate level, but genetics is not overtly recognized. For nursing students education standard 2.3 for the Registered Nurse scope of practice specifically requires students at the graduate level to demonstrate;

- pharmacology knowledge and medicine management
- comprehensive health consumer assessment skills and clinical decision-making skills supported by knowledge of pathophysiology
- therapeutic communication with health consumers
- working within a health care team; providing direction and delegation in practice
- the use of information technology and health information management (Nursing

Council of New Zealand, 2015, p. 6)

Similarly there is no element of genetic competence in the national standard for registered nurses in New Zealand (Nursing Council of New Zealand, 2012). Registered Nurses' competencies 2.4 and 2.7 ensures the health consumer has adequate explanation of the effects, consequences and alternatives of proposed treatment options, and provides health education appropriate to the needs of the health consumer within a nursing framework, are the most relevant (Nursing Council of New Zealand, 2012, pp 17-20).

The current expectations of registered nurses is important to address because currently there is a phenomena of New Zealanders being exposed to genetic ideas, conversations, and questions yet there is a potential lag between this exposure and the answers and information available from nurses. For example, Freeview TV airs shows called 'The DNA Detectives', The New Zealand Listener has published six relevant articles in the last two years (New Zealand Listener, 2015), the Australian Women's Weekly online has 116 articles related to 'genetics' (Women's Weekly, 2016) and the Otago Daily Times published no less than 15 articles in December 2015 alone containing the words 'gene' or 'genetic'(Otago Daily Times, 2016). The DNA Detectives was referred to by a nurse in the focus group in regards to the publics' increasing exposure to genetics in mainstream media.

Sociopolitical Context 2: Genetics and New Zealand

In 2006 New Zealand had the *perfect storm* (emphasis my own) regarding genetics in the media. From this time it could be argued that genetics has become a sensitive topic and almost taboo to talk about in regards to Māori. In 2006 three-month old Māori twins died of head injuries and the Prime Minister described the family as a "once were warriors type family" (Newstalk,

2006). Shortly after this it was announced that a genetic polymorphism had been identified associating higher levels of MAO (monoamine oxidase enzyme) in Māori (Lea & Chambers, 2007; Perbal, 2013). Previous studies had linked this polymorphism with aggressive behavior, mental retardation, lack of self-control, addiction and risk taking behaviors and so it became known as the warrior gene (Cases, Seif, Grimsby, Gaspar, Chen, Pournin et al., 1995; Gang, 2004) or the "disease of being Māori" (Hook, 2009, p. 1).

In a country where Māori are stigmatized for addictive behaviors and endemic domestic violence this pseudoscientific term "play[ed] with the imagination of the public" (Perbal, 2013, p. 385). It created a space where it was considered scientifically sound to believe Māori are predisposed to be aggressive and impulsive; supporting a war-like stereotype. Although now considered unjustifiable, the event used "western science to perpetuate racist and oppressive discourses" (Wensley & King, 2008, p. 507).

Within the scientific community there are significant case studies regarding working closely with Māori and their genetics; particularly around inherited disease. For example, Professor Stephen Robertson, a pediatric geneticist from the University of Otago, worked closely with four generations of a Māori family to identify Otopalatodigital syndrome (Robertson, Walsh, Oldridge, Gunn, Becroft, & Wilkie, 2001). This syndrome is an inherited disease linked to the X chromosome and while type 1 had previously been identified it was the more lethal allelic variation (OPD2) that this family was carrying (Robertson, Gunn, Allen, Chapman, & Becroft, 1997). The mutation is more severe and often lethal to males due to the X linkage (males only have one X chromosome where females have two). For the Māori family Dr. Robertson worked with the allele was entirely lethal to males (all boys died perinatally); of note, under development of the thorax is often the life limiting factor. Carrier females can develop skeletal facial dysmorphism and skeletal

deformities around the ear can make conductive hearing loss a related symptom (Robertson, 2007). The unusually high rate of male infant mortality originally lead the family to believe they were carrying a curse (makutu) and their burden was lifted by assuming ownership of the genetic test and results (Port, Arnold, Kerr, Gravish, & Winship, 2008). Contrasting with the unfortunate warrior gene event, here the discovery of the relationship between genotype and phenotype of OPD2 was only possible by the relationship and close personal ties that Professor Robertson developed with the whanau, their stories of loss and the respect he showed for the whanāu's ownership of their DNA and the genetic test (DeBose, 2004).

Dissertation Structure

This dissertation has been divided into four further chapters. Chapter two places the research in academic context with a brief literature review which reveals four fundamental themes in the literature related to nurses' communication of genetic concepts.

Chapter three outlines the development of the research question 'how do registered nurses in the New Zealand setting participate in genetic conversations'. The justification of using a single small focus group informed by the methodology of Richard Krueger is discussed. This chapter also outlines the design decisions, including ethical consent processes and how rigor has been incorporated into the methodology. This chapter outlines specifically how the methods were implemented including recruiting and sampling decisions and pragmatic details of running the focus group and editing the transcript.

The analysis of the group data is discussed in Chapter four with details regarding the use of systematic thematic analysis to generate data. Here four prominent themes were identified and are discussed in detail. Chapter five draws from the previous four chapters to provide a discussion about the imperative of moving the discussion of nursing and genetics out of the biomedical space and into a nursing framework and way of thinking. A simple tool to guide nurses in their genetic conversations is presented and the dissertation concludes with recommendations that will facilitate a way forward.

CHAPTER TWO: REVIEW OF THE LITERATURE

An initial review of the literature in April 2015 was completed specifically looking at the concepts of nurses, communication and genetics. The methods are outlined below. Between April 2015 and October 2015 this review was extended and developed to include the more abstract themes that emerged from time immersed in the literature and further exploration from discussions with both peers and experts.

Aim

The aim of the April 2015 literature review was to assess and critique the existing literature to determine what information already existed and what conclusions have been drawn about how nurses communicate genetic concepts. The review identified gaps in the literature and was used to refine and develop the research question.

Methods

In order to develop an extensive and relevant literature review three electronic databases were searched; CINAHL, Ovid Medline and the Joanna Briggs Institute EBP database. Hand searching of reference lists was also conducted. Key search terms were nurs* AND genetic* AND communication. However, no papers were found that directly address these terms so the search was extended in consultation with a subject librarian to include; nurs*, genetic* OR genetic counseling OR genetic counselling, nurse patient relationship, genetic concepts, communication, patient education, Māori OR New Zealand OR Indigenous population. The search term combinations and results are in Appendix 3. Due to the small number of results all were included regardless of date or peer review status and the results were hand sorted to find relevant and appropriate literature.

Search outcome

During the April search a total of 296 references were collected of which 65 were duplicates and 161 were published post 2005. Of those published in the last 10 years 24 included the concepts of nursing and genetics while 22 older references included both concepts. There were no articles that included the three core concepts of genetics, nurse and communication. Only 6 of the collected papers included the concept of communication. However, these were genetic counsellor based but included in the search as discussed under the theme 'role of the nurse'. There were 9 papers that included New Zealand OR Māori AND genetics.

Themes

A 2012 mixed method systematic review identified five themes in regards to nurses meeting core competencies in genetics in their nursing practice; knowledge, experience in using skills, ethical practice, perceived relevance and confidence (Skirton, O'Connor, & Humphreys, 2012). Reviewing the literature with a focus on communication in place of competencies shifted the prominent themes into a more holistic and historical framework due to the lack of direct literature around the topic. These initially were; the colonisation of genetic counselling, what nurses need to know, and the consequences of information. Over the six months immersed in the topic these themes developed into; future orientated literature, colonisation of genetic counselling, whakapapa and genealogy, and the work of Dr. Gwen Anderson in calling for a paradigm shift.

What nurses 'will' need to know; future orientated literature

The language used in the literature provided the theme of what nurses will, one day, need to know. The majority of the literature is future focused referring to genetics and genomics as the *future* of nursing (Bancroft, 2010; Godino, Turchetti, & Skirton, 2013; Goldberg, Jenkins, &

Spahis, 2010b; Leavitt, 1996; Williams & Tripp-Reimer, 2001). This idea appears annually in the literature (table 1, page 13) and occurs in articles as late as 2014 (Blix, 2014). Articles refer to the fact that nurses *will* play key roles in providing genetic education, advocacy and information. The Oncology Nursing Society of America published a position on the role of the oncology nurse in cancer genetic counseling in 1998 and republished in 2000 (Oncology Nursing Society, 1998, 2000). The position clearly emphasized that as cancer genetics advances the number of individual oncology nurses "must" have educational preparation and that cancer genetic context "must" be integrated to all levels of nursing curriculum (Oncology Nursing Society, 2000, p. 1348). Yet the language in the article continues to be future focused- the opening statement refers to a current change in understanding of cancer yet finishes by saying "the genetic revolution *will* have an impact on the entire specialty of oncology nursing" (Oncology Nursing Society, 2000, p. 1348).

Table 1: Key annual publications of literature regarding the future of nurses and genetics from years 2015- 2000

Year	Title	Key themes	Reference
2014	What your nurse needs to know about Genetics	That nurses are expected to meet competencies but lack educational support.	(Ivey, 2014)
2014	Personalized Medicine, Genomics, and Pharmacogenomics: A Primer for Nurses	That nurses will be patient educators and advocates in the *future* personalized genomic era.	(Blix, 2014)
2013	Providing nursing care and support to individuals and families with genetic/genomic healthcare needs	How nurses can develop confidence and competence in genetic healthcare because they *will* be needed.	(Kirk & Marshallsay, 2013)
2013	The future of nursing: genetics and genomics	Genomics and genetics, particularly screening and counselling, will be in the *future* of nursing practice.	(Bonvissuto, 2013)
2013	The History of Genomics: What Nurses Need to Know	Expanding nurses genomic knowledge.	(Baldia & Morrison, 2013)
2013	How Has Genetic Testing Affected Your Clinical Practice?	Genetics is an exciting *new horizon.*	(Coghill, 2013)
2012	Nurses' competence in genetics: a mixed method systematic review	Nurses are not meeting genetic competencies.	(Skirton et al., 2012)
2012	The Future of Genetics at our doorstep	Educational piece for all healthcare professionals regarding genetics and speech and hearing impairments.	(Peter, 2012)
2012	A systematic review of nurses' knowledge of genetics	Perceived and actual genetic knowledge in nurse's low, educational levels low also. Yet nurses are open to genetic education but it must be relevant and applicable to their practice.	(Godino & Skirton, 2012)
2011	Implications for Educating the Next Generation of Nurses on Genetics and Genomics in the 21st Century	Genetics and genomics becoming increasingly used in healthcare and nurses *will* need to incorporate these.	(Lea, Skirton, Read, & Williams, 2011)
2011	Essential Genetics and Genomics Competencies for Nurses With Graduate Degrees	Nurses need genetic and genomic knowledge to function in today's complex health system and level of genetic competence required has increased quickly.	(Greco, 2011)

2010	Genetics: soon to be part of nursing practice	Genetics *will* impact on nursing practice.	(Goldberg, Jenkins, & Spahis, 2010a)
2010	Nurses transforming health care using genetics and genomics	Nurses have the potential to improve patient outcomes and the use of the US healthcare system when given influence regarding genetics in policy.	(Calzone, Cashion, Feetham, Jenkins, Prows, Williams et al., 2010)
2009	Genetic counseling and the advanced practice oncology nursing role in a hereditary cancer prevention clinic: hereditary breast cancer focus (part II)	The role of the nurse as patient educator and advocate *will* continue to increase.	(Lynch, Snyder, & Lynch, 2009)
2008	Clinical care at the genomic interface: current genetic issues in neonatal nursing	Neonatal nurses have a *growing* responsibility to incorporate genetic competence into their practice.	(Thorngate & Rios, 2008)
2008	Clinical aspects of genomics: an update	Genetic technology increases each year and nurses are, and *will be*, more important in providing patients with information.	(Prows, 2008)
2006	Genomic-based nursing care for women with Turner syndrome: genomic-based nursing care	Nurses have the *potential* to contribute significantly to interdisciplinary approach to patient care by using the information from the genomic era to improve.	(Flória-Santos & Ramos, 2006)
2005	How are oncology nurses meeting the genetic education and counseling needs of patients?	Nurses are expected to provide information but are not yet ready for the *genetic revolution.*	(Lally, 2005)
2004	Genetic discoveries and nursing implications for complex disease prevention and management	Genetics *will* revolutionize how nurses approach patient's healthcare in terms of prevention, diagnosis and treatment of disease.	(Frazier, Meininger, Lea, & Boerwinkle, 2004)
2003	Preparing nurses for a 21st century role in genomics-based health care	A *visionary future* of nurses involved in case management and counselling associated with genetics.	(Lea & Monsen, 2003)

2003	Deconstructing DNA: understanding genetic implications on nursing care	Nurse's role in genetics is well established the challenge is to keep abreast of current knowledge.	(Cook, 2003)
2002	The role of the nurse in cancer genetics	Clinical oncology is already impacted by the Human Genome Project; nurses must adapt knowledge to adjust to the new healthcare.	(Middleton, Dimond, Calzone, Davis, & Jenkins, 2002)
2002	Ask the expert. Meeting the standard of genetic nursing care	Nurses need genetic knowledge no matter what their practice setting.	(Bowers, 2002)
2001	From ecology to base pairs: nursing and genetic science	Opportunities for research nurses in genetics *will increase in future.*	(Williams & Tripp-Reimer, 2001)
2001	Preparing for the future through genetics nursing education	Nurse education needs to increase focus on genetics to meet *future* competencies.	(Jenkins, Dimond, & Steinberg, 2001)
2000	Preparing the nursing profession for participation in a genetic paradigm in health care	Nurses have the ability to provide genetic services but genetics needs to be incorporated into nursing education and practice.	(Anderson, Monsen, Prows, Tinley, & Jenkins, 2000)
2000	Genetics, ethics and education: considering the issues for nurses and midwives	The inadequacy of current education standards of genetics for nurses and midwives is unethical for the current and *future* health needs.	(Kirk, 2000)

This position demonstrates a lag in the literature; between what patients are experiencing today and the idea that nurses are not needed, are not making themselves available, or will not be educated, until tomorrow. While the lag exists, there is a definite body of literature dating as far back as 1962 that identifies a need for the imminent change of nursing education to incorporate current genetic knowledge (Anderson & Monsen, 1999; Anderson, 1996; Brantl & Esslinger, 1962; Cohen, 1979; Williams & Lessick, 2001) and yet multiple authors refer to the fact that nursing education has been unwilling, or sporadic at best, to incorporate the change (Kirk, 1999; Monsen & Anderson, 1999; Williams & Lessick, 2001).

This inconsistency between the academic evidence in the literature and the practical application of it in nursing education supports Thomas Kuhn's concept of a paradigm shift. The concept being that science develops linearly by accumulation of facts and data until anomalies during revolutions (here the sequencing of the human genome) shifts the path in another direction (Kuhn, 1962). It takes time to accumulate enough evidence to swing the pendulum of commonly accepted ideas in the opposite direction and so knowledge lags behind publication.

'Colonisation' of genetic counselling

In 2002 Maurice Nicol predicted the concept of colonization of genetic counselling. The concept is that genetic counselling is a *territory* and one that other health professionals will claim if nurse education does not produce a nurse capable of the role. Her prediction is supported by evidence that in 2002 not all Bachelor of Nursing programs in New Zealand taught any genetics (Nicol, 2002). In America, eight years earlier in 1996, the American Academy of Nurses recognized the immediate need for formal education in the area (Lashley, 1997). Soon after it was recognized that specialist genetic nurses would not be the only ones needing the education; as the science advances the population being nursed moves into specialty clinics, such as cardiology, and

into primary care. Consequentially, the role of counsellor and educator will likely fall to the nurse (Biesecker & Marteau, 1999; Touchette, Holtzman, Davis, & Feetham, 1997; Williams & Lessick, 2001). A 2011 news article from England demonstrates that nurses are an essential tool to genetic services and people when provided with current education and recognized as the asset they are. 'Pre-genetics triage', training which reflects the competencies of genetic nurses (testing, family histories and counselling), reduced referrals to a specialist genetics service by 75%; significantly easing pressure on services and alleviating unnecessary patient fear (Blakemore, 2011). The effectiveness of this principle has been illustrated in America. A white paper, written with the purpose of driving policy change, demonstrated nurses' skills are pivotal (Calzone et al., 2010). The principal concern the 2011 article presented was that pre-genetics triage could not exist without an element of counselling.

A commonality that emerged from the literature that bridged the two themes of 'colonization of genetic counselling' and 'what nurses need to know' was the ambiguity of what genetic counselling is, who is responsible for it, and who plays a role in it; making 'role ambiguity' a major challenge in both the literature and nursing (Bassetti, 2002; Bottorff, McCullum, Balneaves, Esplen, Carroll, Kelly et al., 2005; Godino et al., 2013). Genetic counselling role ambiguity between doctors, geneticists, social workers and nurses resulted in The American Board of Medical Genetics certifying professional genetic counsellors in 1982 due to "territorial disputes" (Lashley, 1998, p. 214). Despite this the role is often filled, in the American setting, by other practitioners; particularly nurses in rural areas and some clinics (Lashley, 1998). In New Zealand during the seminal case of testing rural Māori for the E-cadherin gene related to stomach cancer the whanau asked that genetic counselling be discarded from the testing; they felt their previous genetic counselling needs had not been met by health professionals and they were the ones with

the experience and knowledge to provide the service to their own people (Port, Arnold, Kerr, Gravish, et al., 2008). A compromise was made that a Māori nurse would advise the genetic counsellor on tikanga (Māori custom) and be present at the sessions to provide the additional dimension of cultural values and beliefs to the concept of autonomy (Port, Arnold, Kerr, Gravish, et al., 2008).

A challenge the literature presented was the variation between national health systems. For example, in the American system a 'genetic counsellor' could be an advanced practice nurse while in New Zealand a genetic counsellor is specifically a doctor (Bassetti, 2002; Genetic Health Service, 2015; Lynch et al., 2009). This makes applying American, United Kingdom or European literature to the New Zealand setting inadequate; despite these being the principal contributors to this literature review. In New Zealand a degree of colonization of genetic counselling is apparent between the role ambiguity of the Registered Nurse and the Midwife as discussed in Chapter 1 under the title of sociopolitical context 1.

A paradigm shift: The pioneering work of Dr. Gwen Anderson

During the late 1990's and early into the twenty-first century there were a flurry of articles calling for a paradigm shift regarding how nurses think about genetic information and genetic testing (Anderson, 1998; Giarelli, 2003; Newell, 2000). This shift called for genetic nursing to have a holistic foundation; that is, one that sees the person as a whole and moving away from the hard science (Anderson et al., 2000). To do this the literature often cites story telling as new best practice; enabling the person to tell their personal stories in order to know them better as an individual and to prevent the influence of others dominating patients' decision making regarding genetic testing (Anderson, 1998; Anderson, 1999).

Dominating the literature is the work by Dr. Gwen Anderson. Four principal holistic nursing practices were identified by Dr. Anderson; honoring the patients personhood, knowing the whole person, uncovering power imbalances, and listening to their values and beliefs (Anderson, 1998, p. 65). Anderson's work is based on the nursing theory presented by Benner (Anderson, 1998, p. 75; Benner, 1984). Evidence and theory based, Anderson's work provides a solid intersection of the nursing literature and genetics. The idea of storytelling is adapted by the genetic counselling literature also but can differ between whose stories the author believes are important; that of the patient or the *expert* referring to the clinician (Ettorre, 1999; Ordonez, Margarit, Downs, & Yashar, 2013). This sharing of a pivotal paradigm illustrates the idea clearly regarding which profession has *colonized* the territory of genetic counselling; does it belong solely to those with the title or can nurses fill the role as well? Anderson defined genetic nursing in 1998 "to include all nurses who have a basic knowledge of genetics who can recognize a clinical genetics question or a nursing situation" (Anderson, 1998, p. 65). Today, 17 years later, it would be fair to say that all nurses now fill this description.

When whakapapa does not equal genealogy; genetics and family

Genetic services in New Zealand come from a Eurocentric base consistent with Western values in medicine of informed choice, autonomy and empowerment (Port, Arnold, Kerr, & Winship, 2008). When Western models take precedence then the dominant culture defines what is important. Part of this defining in New Zealand includes defining words of other languages to best suit. An example of this in regards to genetics is the term 'whakapapa' which is a Māori term often simplified in the literature to mean 'genealogy' (Puhiawe, Horotakere, & ki Kawhia, 2008; Taupo, 2012).

From a biomedical model this makes the idea singular and linear, yet within a Māori world view this is only a fraction of what whakapapa means. For example:

- Genetics: The study of heredity and the variation of inherited characteristics; the basic unit of heredity is the gene which is made of DNA
- Genealogy: A line of descent traced continuously from an ancestor.

Similar concepts exist in Māori thinking;

- Ira tangata: the human element or life principle; the basic biological essence of human-ness
- Whakapapa: the relationships and genealogical connections that build out from or upon this base.

(Ahuriri-Driscoll, personal communication, November 11, 2015)

Within both views there are narrow and broad concepts. Reductionism in Western thinking considers all but the biological relationships in whakapapa unimportant but in indigenous Māori thinking all are celebrated (Ahuriri-Driscoll, personal communication, November 11, 2015).

Graham (2009), quotes Barlow as saying " whakapapa is the genealogical descent of all living things from the gods to the present time…" (Barlow, 1991; Graham, 2009, p. 173). Standing alone this sentence synonymizes whakapapa with genealogy, but it is the one that follows that distinctly separates the two concepts; "…whakapapa is a basis for the organization of knowledge in the respect of the creations and development of all things" (Barlow, 1991; Graham, 2009, p. 173). A modern description of whakapapa is extended to be "the foundation of traditional Māori social structure and it perpetuates a value base that locates people through their relationships to the physical and spiritual worlds" (Hudson, Ahuriri-Driscoll, Lea, & Lea, 2007, p. 43). The

importance of this concept is evident in Graham, who stated that "whakapapa is the credential that gives the author license to be Māori" (Graham, 2009, p. 2).

Concern has been raised about the narrowing of the definition of whakapapa to genealogy and a qualitative study from the University of Otago bioethics department identified that for Māori, there is more to identity and lineage than biological ancestry (Evans, 2012). In this widely globalized age very few places remain with a singular culture and New Zealand is no exception. Despite this, science predominately trumps as arbitrator of knowledge and a positivist paradigm persists (Richardson, 2004).

In nursing literature, and supported by the Nursing Council competencies, is the idea that this idea of singular and linear interpretations has shifted towards a post-modern view; recognizing that there are multiple interpretations of reality (Richardson, 2004). Competency of a New Zealand nurse includes practicing with cultural safety; a "critically reflective concept embodying the need for acceptance (rather than assimilation) of variance" (Richardson, 2004, p. 40). What this concept means for nurses is recognising, and acting on the fact, that not every person holds the same world view, including a biomedical approach to health. An example of this was demonstrated when a Māori family with a young woman carrier of a gene for adrenoleukodystrophy refused prenatal testing when she learnt she was pregnant with a male child; her wishes to refuse testing were denied by the kaumatua (elders) of her family (Port, Arnold, Kerr, Gravish, et al., 2008, p. 136). The view of autonomy and informed consent differs within a Māori worldview compared to a western biomedical model; the strong influence of hierarchical tribal structure sees autonomy through a collective rather than individual lens (Port, Arnold, Kerr, Gravish, et al., 2008).

A 2012 masters project recognized a phenomenon of when talking about genes, tests and medicines Māori participants talked with reference to a web of spiritual and cultural contexts, life

processes, and iwi and hapu ontologies and epistemologies (Taupo, 2012). One participant in the Otago University study summed up how he made decisions about genetic technologies by saying he "would not want to see my whakapapa torn up or misused in anyway…protecting whakapapa, which is at the end of the day protecting my whanau" (Evans, 2012, p. 187).

Whakapapa and genealogy are linked to 'whanau' in two ways; as the transmitters of ira tangata and as the embodiment of whakapapa (Ahuriri-Driscoll, personal communication, November 11, 2015). Within the literature there is a distinct difference between genealogy and whakapapa, but this difference often appears insignificant and is overlooked. But when the conversation comes to be about genetics in the New Zealand context the difference becomes fundamental and one that is at the very heart of what 'genetics' and 'family' means to individuals.

Gaps in the Literature

From the three central themes that the literature presents there are some fundamental gaps in existing knowledge about how nurses communicate genetic concepts. There was no literature found that directly linked the three concepts of genetics, nurses and communication. Of the literature around the generalized concepts of the topic it is clear that role ambiguity is a significant challenge to nurses and understanding what is expected of them. While international standards exist for these expectations, the literature suggests there is insignificant evidence to determine if these are being met. Evidence comes predominately from the American context with a focus on specialized advanced practice nurses. Evidence is lacking in regards to nurses as a generalized group, New Zealand nurses and about specific communication interactions such as answering questions on genetics or managing the distress communication may cause.

The next chapter outlines the design and implementation of the methods used to answer the research question about how a small group of NZ nurses engage in genetic conversations.

CHAPTER THREE: RESEARCH AIM, DESIGN AND IMPLEMENTATION

Research Aim

This project aims to explore how nurses respond to, initiate, communicate, or interact in situations where the concept, topic or ideas about genetics arise.

Research Question

From the identified gaps in the literature the research question was developed. Figure two (p. 24) illustrates the refinement process of developing the research question. The following five points, corresponding with the numbers on the figure, demonstrate the rationale and justification behind the evolution of the question.

1. Identifying why this gap in the literature exists cannot be quantified; the conclusions have not been drawn to pull statistics from so this area requires a study that aims to understand the phenomena and/or explore the experiences within it. The initial question found no direct answers in the literature, and so *understanding* the phenomena cannot be achieved because there is no evidence that they have been initially *explored* yet.
2. There was a distinct gap in the literature regarding New Zealand nurses. The term New Zealand nurses changed to 'nurses in the New Zealand context' to avoid nationality confusion.
3. The precise component of communication to be explored is both broad and specific; 'conversations' in the general sense and 'conversations' in the specific sense of the aspect of communication of speech interaction.
4. 'Engage' is too specific in that it could refer just to the aspect of beginning. 'Participate' is general and can refer to all aspects of the conversation and does not exclude those events where nurses do not 'engage'.

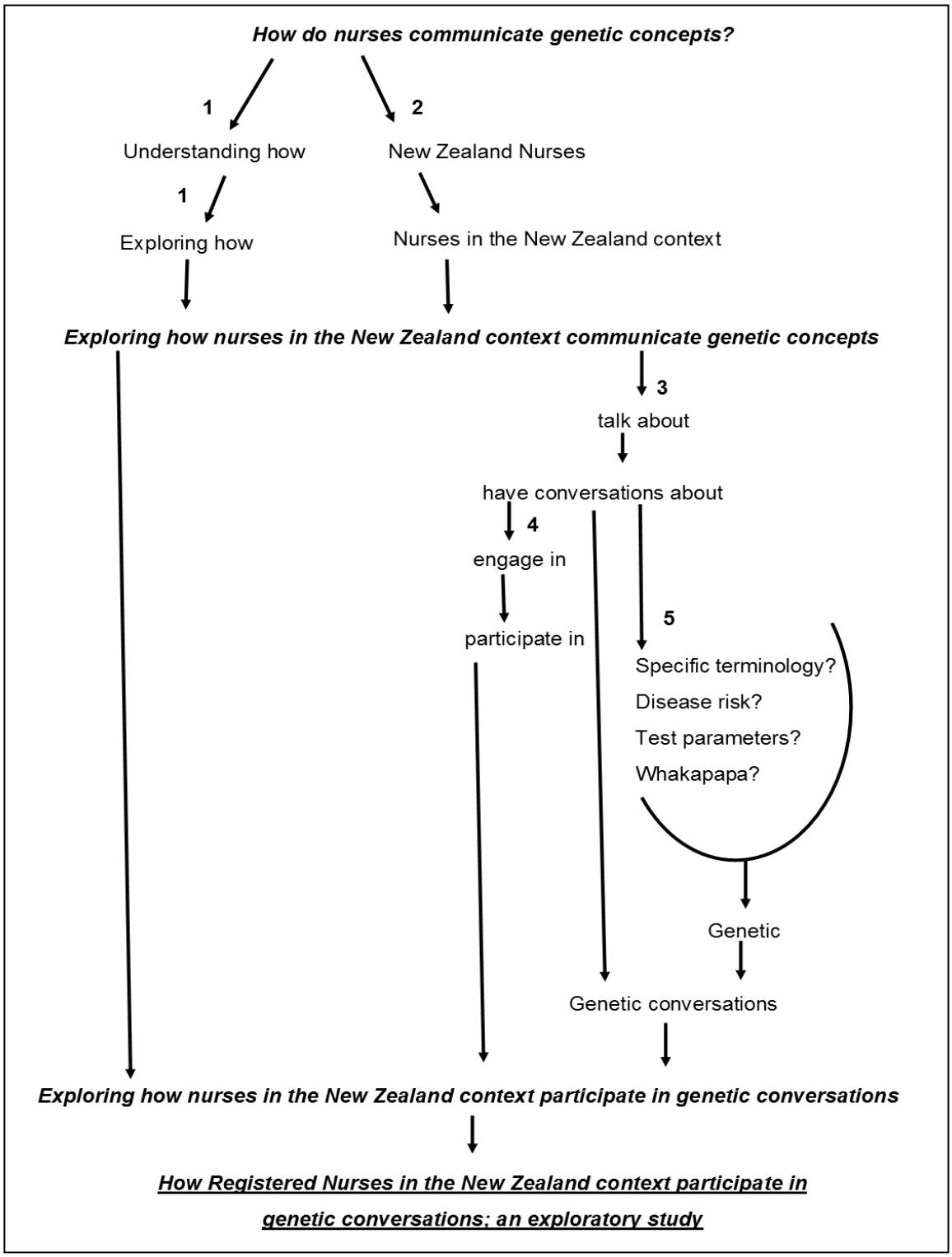


Figure 2: Refinement process of research question

5. What 'genetic concepts' mean to different people vary; it is an ambiguous term so needs to be kept in the broad sense to be able to accommodate people's different understandings of it. For example recognizing that whakapapa does not translate directly to mean genealogy; although it is the closest approximation it is an over simplification (Evans, 2012). Considering that whakapapa is the core of what it means to be Māori (Cheung, 2008; Te Rito, 2007; Walker, 1993); a holistic or traditional world view makes this mean a very different thing to someone who holds a reductionist or scientific world view.

Research Objective

Conduct a single, small focus group to explore ideas around how nurses respond to, initiate, communicate, or interact in, situations where the concept, topic, or ideas about genetics arise.

Ethical Approval

Ethical approval from the University of Canterbury Human Ethics Committee was granted 2nd September 2015 and the project was considered low risk (Appendix 4). Local authority from the principal local hospital was required and granted 1st October 2015 (Appendix 5). Due to insufficient recruiting a second local hospital was contacted which had their own internal ethical approval system. Approval was granted 29th September 2015 with the request they be provided with report of outcomes and/or any publications (Appendix 6). Due to low recruiting returns during the first drive, 15 Professional Development and Recognition Program (PDRP) hours were offered as incentive during the second round. The amendment was approved by University of Canterbury Human Ethics Committee 29th September 2015 (Appendix 7). Māori consultation was required as protocol through the local hospital internal ethical process. There was initial concern regarding the

position of Ngai Tahu and Māoridom and the study of genetics (Appendix 8). Approval was granted by the chairperson for Māori consultation 30th October 2015 and they have asked for a final report on the conclusion of the project (Appendix 9). The Executive Nursing Director of District Health Board and the Directors of Nursing from included hospitals were notified of research (Appendix 10).

Research Methodology

Focus Group Rationale and Theory

Exploring an area requires investigation of responses, attitudes, and behaviors; concepts that must first be understood before they can be counted; requiring a qualitative perspective (Silverman, 2005). In the natural progression of developing knowledge, exploring what phenomena is occurring, such as this research question is doing, precedes *why* that event is happening or *what* it means. Using a focus groups to collect this data meets this need; it encourages participation, for people to share stories, ask questions of each other, and make comments- enabling the researcher to explore not only what events are occurring but also how and why (Kitzinger, 1995).

A focus group is "unstructured interviews with small groups of people who interact with each other and the group leader. They have the advantage of making use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth" (Freeman, 2006, p. 491). Focus groups provide access to data the other forms of qualitative data collection cannot (Morgan, 1997). This method has the benefit of the group process facilitating people to explore and clarify their own views in a way an interview does not allow for (Kitzinger, 1995). With a topic that some people may believe they have nothing to offer (nurses talking about genetics) (Godino et al., 2013), focus groups allow for the group process to illuminate shared

knowledge or group culture that is otherwise inaccessible to the researcher (Hughes & DuMont, 2002). This has been demonstrated by focus groups used to effectively explore attitudes of health staff in previous studies (Brown, Lent, & Sas, 1993; Denning & Verschelden, 1993).

Use of epistemology to guide best practice

What best practice is in designing a focus group, particularly in sampling methods, depends on the epistemological assumptions the research question presents. Within qualitative research competing epistemological strands can be generalized into 'realism' and 'constructionism' (Freeman, 2006). This research is guided by realist assumptions due to the inherent nature of the proposed research question. The alternative constructionist epistemology rejects the idea of a single reality, which the New Zealand context of genetics challenges by way of alternative world views. Since data is considered rich when sourced from multiple points rather than by finding consensus (Freeman, 2006) it does not link this research question to an applicable outcome. This question aims to explore how New Zealand nurses participate in genetics conversations by using a focus group. The link between question and outcome relies on the assumption of the ability of the method (focus group) to provide transferable data, or external validity, to apply to the wider population. Thus, best practice for this research is guided by distinguished realist qualitative researcher Richard Krueger.

For this research a single small focus group was used to collect data. While best practice considers 3-5 separate groups to be optimal (Krueger, 1993) the time and resource constraints of this project meant one group was sufficient. This project does not aim to provide a comprehensive view of how nurses participate in genetic conversations, rather it aims to provide a beginning to the conversation. One group with a minimum of 6 participants held over an hour has the potential to generate sufficient data to do this. Between 6 and 10 people is considered ideal

for an individual focus group (Krueger, 1993). Due to the literature providing evidence that many nurses feel they have nothing to offer regarding the topic (Godino et al., 2013) a group smaller than six people has a considerable chance of yielding very little data or being considered invalid. The balance between overwhelming or insufficient data with the aim of the methodology to produce transferable data, or external validity, makes a minimum of six participants' best practice.

Triangulation

From a realism position triangulation is the process of fixing or capturing a single location based on the logic that truth or *accuracy* is increased by multiple measurement (Cox, 2008). Some argument exists for the need to *capture* a single location with discussions about the reflexive stance of the researcher (Cox & Hassard, 2005). This moves the focus from what is *inside* the triangle to who drew it and *how*; alternatively, that methods are more reflective of the accuracy of a piece of research than results. The perspective presented by Cox and Hassard, 2005, of "the researcher as the finder of a particular angle'' (p. 110) is one which resonates with the ambiguity and infancy of the relationship between genetics, nursing and communication.

There are four types of triangulation; data, investigator, methodological and theory triangulation (Cox, 2008; Denzin, 1970). Data triangulation is the process of collecting data from multiple sources. Due to the limitation of this research to a single focus group, data cannot be triangulated this way. Instead triangulation comes from investigator and methodological triangulation. Methodological triangulation is considered by some as compulsory for research to demonstrate method rigor (Bloor & Wood, 2006). The use of two facilitators at the focus group incorporates investigator triangulation into the process. Input data for this work comes from three points; the focus group, the research assistant taking field notes at the group, and the principal

researcher's reflexive journal used over the research journey. These three input points provide three independent methods to corroborate for the analysis thus providing methodological triangulation.

Incorporation of Rigor into Methodology

While rigor is considered as being reflective of a reliable and valid study (Doody & Noonan, 2013; Kidd & Parshall, 2000), demonstrating it requires explicit demonstration of the trustworthiness of the research (Saumure & Given, 2008). In order to meet trustworthiness there are four criteria that need to be met; credibility, transferability, dependability, and confirmability (Shenton, 2004). These four criteria were originally articulated in 1981 to support the validity of qualitative research but are still widely used today (Guba, 1981; Shenton, 2004) This research has been designed to meet these criteria as best as possible given its pragmatic restraints. For example, credibility was incorporated into the design by ensuring enough time was allowed for participants to receive a physical copy of the transcript by post, read, edit and return to the researcher by pre-paid post. How each of the trustworthiness criteria and quality factors have been incorporated into the methodology is outlined in the following two tables. Table 2, p. 30, uses Lincoln and Guba, 2004, Framework for Trustworthiness. Table 3, p. 31, uses the '10 Quality Factors in Focus Group Research' by Krueger, 1993.

Trustworthiness Criteria	**Action taken to meet criteria**
Credibility	• Allow participants to review transcript and final analysis; credibility established if participants agree with the interpretations of the researcher. • Address reflexivity by use of two facilitators and development of reflexive journal by researcher.
Transferability	• Provide a description of the participants included by providing descriptions of demographics and boundaries of the sample.
Dependability	• Use of consistent methods as outlined by reputable published qualitative researcher Richard Krueger based on epistemological position of research. Method to be published in a way it could be repeated.
Confirmability	• Inclusion of deviant case analysis • Have data reviewed by supervisor to ensure themes principal researcher established are congruent

Table 2: Framework and application for 'trustworthiness' in methodology

Quality Factor	Action taken to meet factor
Clarity of purpose	Focus group has single objective. Is not to be used to make statistical projections to wider population. Aim of research group established in information sheet, consent form and oral briefing.
Appropriate environment	Geographically simple location used. Socio-political environment mitigated as best as possible by selection process. Confidentiality agreements to be signed by all participating parties; including transcribers.
Sufficient resources	Budget prepared as accurately as possible by direct contact and quotes from providers. Time resource limited so method adjusted to meet this (running only 1 group rather than optimal 3+).
Appropriate participants	No convenience sample used. Purposeful sampling via self-selection. Segmentation integrated into method as best as possible. Compensation not emphasised.
Skilful moderator	Two moderators (facilitators) present at focus group and post group debriefing.
Effective questions	5 open questions phrased in simple terms which allow for facilitator follow up or 'probing'. Participants asked to identify 'problems' and experiences rather than 'solutions'.
Careful data handling	Use of second facilitator (research assistant) to take field notes during focus group. Professional recording equipment and transcriber used to maximise quality of final transcription. Facilitator debriefing immediately after focus group. Use of reflexive researcher/facilitator diary to limit 'forgetfulness' factor.
Systematic and verifiable analysis	Analysis to follow published method by Kruger and Casey 2010.
Appropriate presentation	Sufficient time allowed for editing of draft results into clear, concise results. Sufficient time allowed for unforeseeable events such as group meeting postponed. Dissemination of results matches research objective.
Honoring participant, client and method	No deception to be incorporated at any stage into method, analysis or results. At all times the topic, participants and ideas to be respected.

Table 3: Application of the 10 Quality Factors in methodology

Sampling

This research aims to generate an understanding how nurses, particularly nurses who do not specifically work in genetics, interact with genetic concepts. Therefore it is logical to include nurses from areas where genetics is more likely to appear as a *co-morbidity* than a primary presentation. Due to the potential that these interactions are a rare occurrence it is reasonable to sample nurses from an area of high throughput thereby increasing the chances of any individual having an experience to bring to the group.

Demographically, and for the reasons outlined above, nurses were sampled from a local public hospital. Cultural considerations in this environment are predominately ward-based. For example the culture of an oncology ward is different to the culture of an accident and emergency department. Nurses share a homogenous nursing culture; an element of homogeneity within the group has been identified as important for enabling candid discussion (Hollander, 2004). Conversely, sampling from different ward cultures provides an element of diversity; identified as important in creating a rich data set (Morgan, 1996). When recruitment was initially insufficient it was extended into a second local hospital. Then the second drive was too successful so the inclusion criteria was tightened to specific SN level; SN5. Selection of who would participate was defined by pragmatic restrictions; those able to make a certain time/location given rostering and other commitments. In order to remove selection bias participants were selected by a first in first served basis.

Inclusion and exclusion criteria

The initial selection criteria for inclusion to the focus group is Registered Nurses from SN1-SN5 (the New Zealand Nurses Organisation (NZNO) pay scale.). Initially exclusion criteria was unit nurse managers, clinical educators, specialists or any Registered Nurse working in a

position other than as a SN1-SN5 ward nurse. Appropriate exclusion criteria is important so that answers are candid and not restricted by hierarchical opinions or power relationships. Acknowledgement that a situation could have been managed differently had the nurse acted or said something another way, could conceivably put participants' at risk. This risk is mitigated for those sharing their experiences by excluding RN's in positions of power or influence from the focus group. Segmenting the group (removing people with power) is recognized by Krueger as important in order for important information to be exposed (Krueger, 1993). The inclusion criteria was adjusted to accommodate those participants who could attend the group to be SN5 level nurses including those working in specialist roles.

Implementation

Recruitment

Sampling was achieved through self-selection by registered nurses, in response to advertisements for the project (Appendix 11). This is justifiable due to the inherent ethical consideration to be taken into account when asking individuals to discuss events that have the potential to reflect their professional practice and/or the nursing care they have provided to people. This method also reduces the effect of facilitator bias in the sense the facilitator has very little to no control over who will reply to the advertisements. Self-selection sampling from different wards addresses a criticism of convenience sampling; that pre-existing groups have pre-existing group dynamics and both formal and informal hierarchies (Freeman, 2006).

Advertising posters (Appendix 11) were distributed 2nd October 2015 in common areas of the hospital including staff rooms of children's, respiratory, endocrinology, rheumatology and oncology wards. A second round of posters were distributed around the hospital at lunch time 14th

Oct; all cafes onsite were visited and posters dropped on each table, posters were distributed to every ward and asked to be placed in staff rooms and on tables at nursing handover including women's hospital. The poster was distributed via internal email system on global update and placed on the intranet staff noticeboard. Responses were received from a nurse specialist and clinical genetic specialist asking for results of project. This lack of participants necessitated a rethink of the sampling strategy.

A revised strategy was enacted 29th October and included a redesigned poster (Appendix 12). This poster offered 15 hours PDRP and a certificate as evidence for participants to use as meeting Nursing Council registered nurse competency 4.3 for their clinical portfolio. Ethical approval was sought and received for this amendment (Appendix 7). The new poster was distributed via electronic means only; included in the daily update sent to all district health board staff, sent out to all nurses via a separate email and posted on intranet staff noticeboard. From this drive 1 nurse made contact via text, 1 left a voicemail and 42 emailed. During this time an inpatient from the hospital made contact and recalled his family story about inherited genetic disease and offered his support to the project.

Participants

Those that made contact were emailed a standard response thanking them for their interest and outlining the inclusion criteria, what the project involved and what it was for. Some individuals asked specific questions which were answered via email. When potential participants responded with their inclusion criteria there were instances when what they stated did not match their signature line. Therefore an inclusion criteria form was added to the information pack sent to all participants that potentially met the criteria. This pack included the information sheet (Appendix 13), consent form (Appendix 14), focus group ground rules (Appendix 15), inclusion criteria form

(Appendix 16) and a return post envelope. Participants were asked to return their signed consent forms via the envelope if they wished to be involved in the project.

Once thirty packs were posted those that contacted me after this time were told that the group had been filled and thanked for their time (a total of twelve people). Those that returned consent forms were asked what time and location best suited them and from these responses, Friday 6th November between 1530 and 1700 hrs was chosen as this suited twelve people. Once confirmed, only five were able to attend. At this stage the remaining twelve participants who did not receive a physical information pack were offered a late-notice opportunity to attend the group and emailed an electronic version of the information pack. The inclusion criteria was extended from SN5 only level nurses to be SN5 level nurses and SN5 nurses in specialist roles due to the type of nurses registering their interest. Three additional people who met the inclusion criteria were able to attend and they returned scanned copies of their consent form to the researcher via email before participating. From this one person withdrew on the day of the group and a total of seven participants attended the group.

Data collection methods

The physical collection of data was done by facilitating the group within a conference room of a local public hospital in order to reduce geographical challenges of data collection. There are three forms of data that focus groups provide; conversation including tone of voice, silences, both of words and of topics and body language (Grudens-Schuck, Allen, & Larson, 2004). The conversation was collected by a voice recorder and a research assistant seated at the back of the room. This person is essential to capture the remaining data forms voice recording alone will fail to accurately capture. Kruger (1993) affirms two facilitators, the researcher as primary facilitator and a secondary facilitator (the research assistant), as a recognized strategy to

achieve quality data collection (Krueger, 1993). Data collection is influenced by a realist approach; due to the inherently complex nature of the topic of genetics the interaction between group members is an instrument for data gathering rather than being the actual data in itself (Belzile & Öberg, 2012; Freeman, 2006).

Research Assistant Responsibilities

The research assistant was responsible for setting up the meeting room, welcoming participants, organizing the refreshments, checking the recorders and taking field notes. She signed a confidentiality agreement prior to the group starting (Appendix 18). The room was set up for the group by having tables and chairs in a comfortable circle so everyone had adequate room and could see each other. The participants were welcomed by the research assistant who offered afternoon tea and introduced them to other members of the group in order to allow the researcher to organize consent forms and interact with the participants to gauge group dynamics. The research assistant had her own table and chair at the back of the room where she took field notes and had a secondary recording device she could monitor at all times during the focus group. The field notes represented group dynamics, emphasis on points and emotions the transcript analysis would not be able to provide.

Running of the Focus Group

Afternoon tea including food and tea and coffee was self-catered by the researcher with family assistance. Participants were invited to join the group at 1530 for afternoon tea and introductions before commencing the focus group proper at 1600. All participants arrived at or before 1530. Due to the size of the room participants found circulating difficult and all choose to seat themselves in order of arrival. This meant that once the last participant arrived and introductions were made talking naturally ceased and it was logical to start the group early.

Once all seated the researcher, acting as primary facilitator of the group, introduced herself and the research assistant and reiterated that the research assistant was not a participant but would be taking field notes of the group discussion. The group was then asked to review the focus group ground rules and asked if any amendments needed to be made. There were none.

It was confirmed that everyone had read and understood the information sheet and the participants were asked if there were any questions or concerns that they felt needed to be addressed before the recorder was turned on. One participant asked how 15 hours PDRP could be offered and it was explained that it was an estimate of how much time participants would potentially invest in the project once the hours for attending, reviewing and editing the transcript was accumulated. It was also explained that the nature of the project; in the sense that participants knew what the topic was before attending, gave the participants time to reflect on the project and their experiences between attending and reviewing the transcript and this time was significant. There were no further questions and the recording devices were turned on.

The group discussion was started with the preliminary question of asking for a working group definition or ideas around what a genetic conversation is. The discussion initially flowed poorly and required facilitator input to move the conversation forward. A set of preliminary questions were developed at time of application for ethics approval to initiate a dialogue (Appendix 17). Once the participants began sharing their work, and sometimes personal, stories the participants realized they all had something significant to contribute the discussion flowed free and only halted and required a facilitator push occasionally.

At the end of the focus group after participants had left the research assistant gave her summary of the group discussion, provided feedback and clarified field notes with the researcher.

Analysis Methodology

Data analysis and interpretation methods

Due to the nature of the research question being based on realist epistemological assumptions and the design of the focus group reflecting best practice principles outlined by realist Richard Kruger; it is logical that the data be analyzed using Kruger's published systematic analysis process (Krueger & Casey, 2014; Rabiee, 2004). This framework outlines four critical aspects of quality analysis; systematic, sequential, verifiable, and continuous. Tape based analysis is within the resource restraints of this research; it can be prepared by the facilitator using a transcript of the recorded group conversation using field notes and facilitator debriefing. From the transcript themes were identified by coding as per the classic systematic analysis method as outlined by Kruger and Casey (2014). Inbuilt into the design of the methodology to meet the trustworthiness criteria of confirmability was the inclusion of deviant case analysis (table 2, p. 30). Deviant case analysis is the process of identifying any opinions or ideas that are non-congruent to the group (Kitzinger, 1995). Instead of being a factor of rigor in the research methodology it is a factor of rigor in the analysis methodology because it can only be incorporated *if* counterintuitive data is collected during the focus group (Wicks, 2010).

The transcript

The audio from the focus group was sent to a professional transcribing service who signed a confidentiality agreement before starting work (Appendix 19). On return of the transcript from the typist it was read through with the audio to check for accuracy. Several inconsistencies were found and edited. These were largely errors of transcription of medical terms the typist was possibly unfamiliar with. Once edited the transcripts were sent to all participants who then had ten working days on receipt of the transcript to review, edit and return. The participants were asked to

review the transcript for accuracy of the overall group discussion rather than their own individual contributions (Appendix 20). All participants made some edits to their copies; largely around restructuring sentences, grammar and removing tangential comments. One identifying factor was removed from the transcript. The participant's contributions and changes were added to the master copy of the transcript. On receipt of the transcripts the participants were emailed to thank them for their time and given a brief synopsis of the project's progress. All participants were mailed a signed letter to recognize their contribution to 15 hours PDRP and meeting Nursing Council competency 4.3.

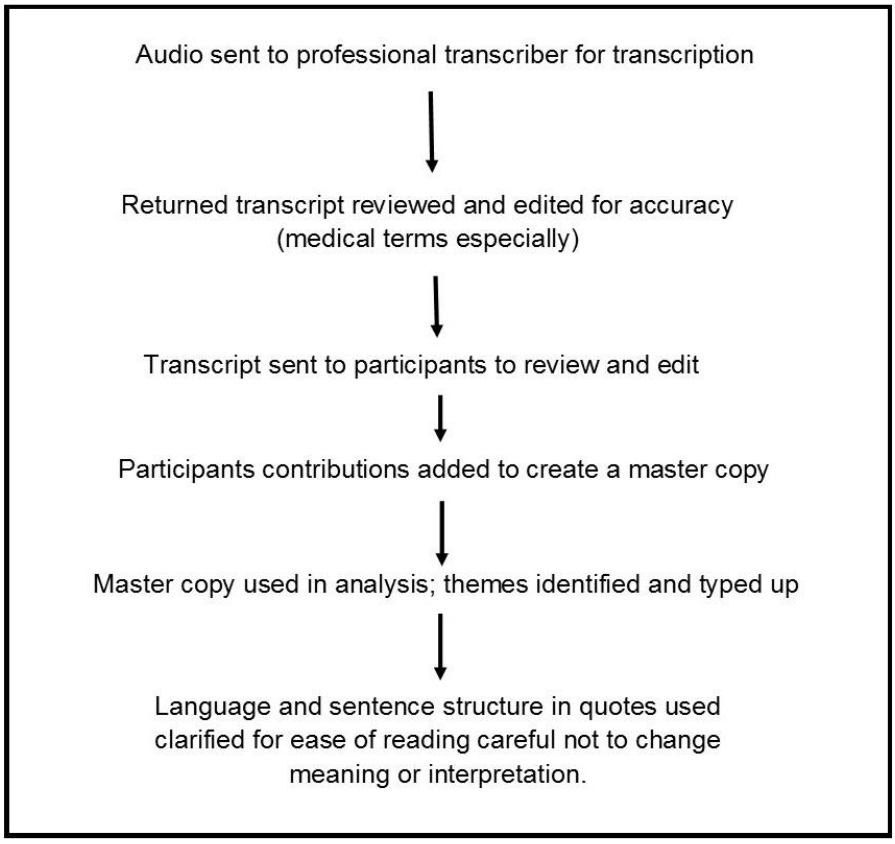


Figure 3: Editing process of focus group transcript

From the original transcript received from the transcriber the editing outlined in figure 3 above occurred to produce the master copy used in the analysis. Examples of clarifying language in the quotes used for analysis is removing repeating "um"'s.

Application of thematic analysis

The master copy of the transcript was printed and cut into individual segments. The segments were placed in a pile and read through systematically with points highlighted. Once highlighted the segments were spread out so they could all be seen at once then arranged into sections of apparent themes that were emerging. Apparently irrelevant sections were put to one side and later reviewed for possible missed concepts. This process follows the classic analysis strategy of Krueger and Casey (2014). The field notes from the focus group were reviewed separately and themes drawn from these to identify differences between transcript analysis and field note analysis. This was important because the field notes held more data about the group interactions. For example, expressing non-verbal cues such as nodding or emotion expressed. The thematic analysis of the transcript evolved and some themes were difficult to distinguish. The field notes and facilitator debriefing enabled me to identify separate themes which were difficult to identify by comparing where emphasis was placed by the participants (in field notes) and what specific language and phrases they were using at the time (in transcript).

The Research Journey; a Summary

Figure 4, p. 41, summarizes the key events of the research journey. It is divided into six sections; developing the research, applying through ethics processes, negotiating access to the field and the first recruitment drive, reinventing the recruiting drive, engaging with participants and running the focus group, and the transcript and actions post group.

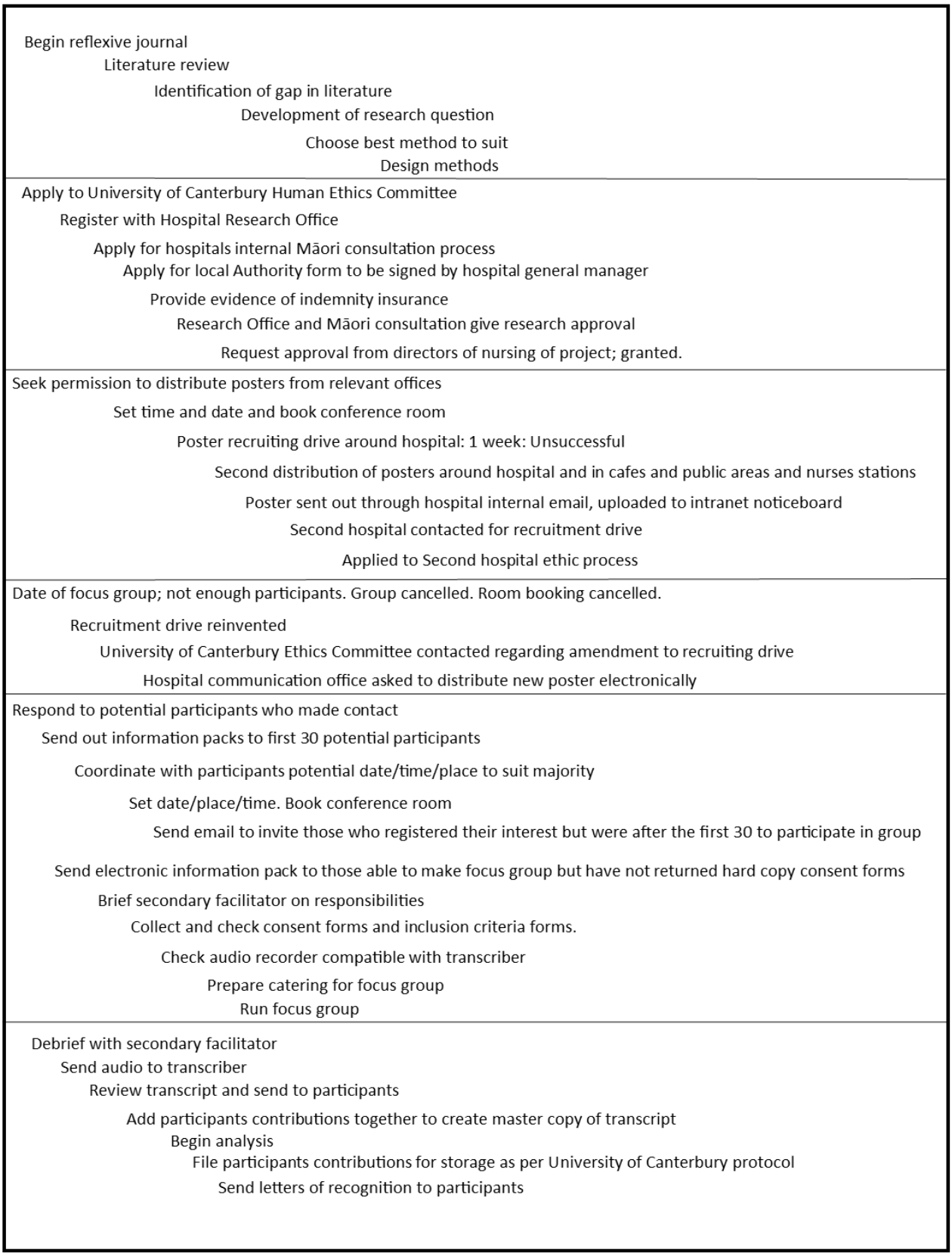


Figure 4: Summary of Research Journey

CHAPTER FOUR: FOCUS GROUP RESULTS

Analysis Themes

Four overarching themes emerged from the analysis and one divergent topic arose. The principal themes were the nurse conversation content; the nurse's role and what is "not my job"; responsibility and blame/fault; and feelings of being inadequately equipped. The theme of the nurse conversation content was subdivided into putting the person in context. During the focus group the concept of 'the ethics of knowing' was an emotive topic which saw different opinions within the group emerge. From the field notes the themes of blame, reliance on technology, feelings of not being equipped and what is 'not' the nurses job were congruent with the transcript analysis.

The nurse conversation content

It was clear at the outset of the focus group and from the questions potential participants had been asking about pre-requisite knowledge to participate that not all nurses believed they had much to contribute to the discussion. The focus group dynamics illuminated that these conversations are occurring more often than previously thought- potentially without nurses being aware of it or the differences between participants' interpretation of family history gathering and a genetic conversation;

> "I don't deal with genetics at all in all honesty. I work in hospital so, you know, patients come in, you're doing all your bits to find out what has happened to the patient, go through the family history obviously but you don't delve so much in to the genetic side of it, you read what the doctors have put then you find out there is a family history of cystic fibrosis or something then the patient sits there and goes 'Oh, I haven't been checked to see if I'm a carrier'." (Focus Group, 2015, p. 7)

> "We actually have that conversation more often than I think. So when we have breast cancer patients in some of them will talk about their family history and they may say I have a daughter; maybe I should have them tested. So it isn't my job to refer that, but I will have those conversations with people and they will want to know, and they will ask me questions about what kind of history they have got and they might talk about their daughters….I'll have that conversation with them, explaining there are genetic components for some breast cancers, I can't initiate an investigation but we can tell patients that there is a valid concern, that they can investigate it, yes. Especially if they have a strong family history." (Focus Group, 2015, p. 9)

The content of the conversations nurses are having varied between participants and it became clear that the level of confidence one participant may have in an area another found very uncomfortable.

> "I am like, 'Yea no, I can't really answer that'- because if we do and it's wrong then you're kind of like 'bugger'. You need to tell them all the information, you can direct them, you know, 'perhaps you could talk to your GP about it' sort of thing, you can go from there. But I don't routinely sit down, I don't have time to sit down for twenty minutes and go, 'Okay, let's have a discussion on your family history'." (Focus Group, 2015, p. 7)

> "Suddenly this IL28B gave us a whole new tool to talk about. I was just saying to a patient yesterday in a few years it'll be completely irrelevant anyway, we won't need to do it because we will be interferon free you know; there will be hope for everyone" (Focus Group, 2015, p. 19)

One participant demonstrated an in-depth knowledge of a specific genetic test and when asked how they presented the information to patients her reply was an invaluable insight into how nurses are making the conversations work for their patients;

> "I keep the information as simple and as clear as possible. Surprisingly I don't get a lot of questions or difficulties with it, but the way I explain it is that everyone in the world will have a result and I will describe what pre-results are, because I keep it simple because I only have a simple understanding too…and you know, if they don't get it I will just say to them 'well, would you like to have the test anyway?' and no-one has ever refused or questioned it." (Focus Group, 2015, p. 6)

It was this 'simple understanding' and reiteration of being 'just a nurse' that was heavily emphasized by the participants in the focus group. This modesty created a safety net that the participants agreed on using;

> "I'm always careful to say what I don't know, I'll say 'I'm telling you out of a fairly deep pool of ignorance here but it's something you might like to think about'". (Focus Group, 2015, p. 27)

Despite this there was evidence that nurses are using critical thinking to contour the conversation to suit the patient;

> " There's that experience element too isn't there, and also contouring how much information you might want to give and what the person wants to know, depends on them, their level of education, reading this- all the information, it's very multi-factorial how that conversation will go" (Focus Group, 2015, p. 18)

There was also evidence of aspects of genomics and epigenetics being applied to conversations despite the nurses being unaware of it. The complexity of genetic information was a common concept that threaded through the focus group and arose under each theme.

> "A lot of genetic information is so complex. You cannot say, you know- well the other thing I say to people with any test is statistics won't tell us what you're situation's going to be so with the testing, or looking at you, and this applies to many things you know, that you really have to have your risk assessed individually but it's as you said, about having that discussion. You know you are trying to prompt towards a discussion, or verify that it is a valid concern, simply discuss it." (Focus Group, 2015, p. 8)

Putting the person in context

What a genetic conversation meant varied between participants and a strong theme that emerged was the idea of genetics helping to put people into context. There were multiple occasions during the group discussion that this idea arose.

> "Frequently when they're not wanting to attend school, and we want to check out if there is any other aspect that has not been formally

> assessed…and there usually is, yip. Once you go down the path of getting them genetically tested then we will usually come across something that is, which you know, it puts context around the difficulties they are experiencing." (Focus Group, 2015, p. 11)
>
> "In regards to genetics, each individual's journey is unique; take people at a different point in time, given their whole circumstances. People are ready to deal with any issue- when they feel the need to know, understand or change things…
>
> ….and then when you're ready, and if they're in the right space, then you can explore that genetic issues, that's really it, isn't it." (Focus Group, 2015, p. 17)

This aspect of seeing the person in their whole context, or holistically was illustrated by a participant at the end of the group;

> "Looking after the patient and what they want and how it is for them, where they are now and how far ahead they may or may not be thinking, they could be in their past or the future, so it's very much about going at their pace, I think that's the main thing because it covers, it's 360, it's their whole, everything about them and who they are." (Focus Group, 2015, p. 27)

What is and what is not the role of the nurse

One clear link was made between the conversation content and the role of the nurse. This was the idea of the nurse being 'left to pick up all the pieces'. Between participants one found it "horrible" while another felt she "quite like[d] that role of being an interpreter back and forth";

> "Often not and I think of the drama triangle so there's only the three people, so you've got the patient, the nurse and then there's the person talking to the patient and the nurse is seen as the rescuer, and the patient's looking at the nurse thinking "please help me, please help me understand" because often it's the nurse who's left to pick up the pieces. They're the ones who, I'm not saying this is a trend, I'm saying that they are the ones who may not put so much jargon, you know, got sort of a more personal understanding in that field and leave out you know- the posh words. So there's the poor patient sitting there looking at all these people and thinking I'm going to look at the nurse because they're my friend you know." (Focus Group, 2015, p. 24)

During the discussion there were points where a clear line was drawn between roles- particularly what was the role of the nurse in relation to the role of the clinician. There was much less certainty between the role of the nurse and the role of the genetic counsellor though.

> "As a nurse your role is just to acknowledge and steer patients who steer the information to doctors who can find something out and something that is relevant" (Focus Group, 2015, p. 19)

> "It [genetics] comes up for breast patients- though it's often covered in consultants' meetings" (Focus Group, 2015, p. 3)

> "The doctors don't necessarily do the education from A-Z. I mean it's a bit like that and genetics, we can walk away or support patients who may have questions but then after you go back for more information, that's where they're trained, well, they're specialists. You know, better we would go through genetic counselling to take people through the whole list of questions, rather than fire away and say we want to test you because we think you might have such and such without wanting an explanation" (Focus Group, 2015, p. 27)

"Not my job"

The concept of 'not my job' or what nurses cannot do was a recurring theme.

> "I don't delve into it a big deal, I know I probably should but then if I did, and sometimes it comes up. A patient said 'Oh what are the chances I am going to die at 55 because my parents dies of heart attacks' I'll tend to say well, we need to talk this through with the doctors, you know, they might be able to do some tests, I don't really, I don't do it, it's not my- not my job. You know that isn't my job. I say it is my job to organize all these tests to find out. So that's where I come from with genetics." (Focus Group, 2015, p. 7)

Responsibility and senses of blame and/or fault

The concept of blame came in two formats; the blame the participant directed at herself and the concept of blame that the nurses felt their patients experienced and the avoidance of the responsibility that they felt drove some of the decision making.

> "You're going to blame yourself for the readmissions because they're continuously sick. I'm thinking of the cystic fibrosis child in this scenario and you know, you could have prevented all those admissions to hospital and got on top of it earlier and so it's stuck between a rock and a hard place, you blame yourself." (Focus Group, 2015, p. 20)

> "I had a child die from it and that was because there was no testing and because they refused the Guthrie test and that was the outcome and the parents of the child, no history, they were alternative, everything will be fine and it's always these kinds of cases that have an outcome of not being fine and you know, how far do you push them to do the test? Do they come back and I mean they didn't, what happened and they just refused, you know, vitamin K injections and all that but how far do you warn them?" (Focus Group, 2015, p. 20)

> "If they did it, or did a genetic test and find out they've got it, is there going to be a sense of blame? Because they think 'Oh my god, it's all my fault'. For example, the only example I can think of is allergies. You know with, when my son was 4 and he got allergies I thought, "Oh my God, it can't be me, because I've got allergies and that's not my fault", well I don't do

> that now, I'm just saying it's like you blame yourself don't you? I mean my parents blame themselves for a cystic fibrosis child in my family and they don't want to be tested because they're too scared to find out which one of them was the carrier and passed it onto their daughter. That's how I would see it, it's like "I did this". I have to be prepared to find out if it's genetic history and don't dwell on it and think 'oh my God, if I hadn't done this, if I'd done it this way' " (Focus Group, 2015, p. 20)

The idea of fault finding was linked back to the conversations content

> "When I worked in the fertility centre, you learnt about a whole lot of say, fertility issues, it's that, "whose fault is it?" you know, and then you're remembering the one time that you might have said it or words to that sense." (Focus Group, 2015, p. 21)

> "That word [fault] just falls out yea" (Focus Group, 2015, p. 21)

> "I had a child with leukaemia and people would say, you know, you wonder why, you know, why and is there any family history etc etc sort of, I just said well doesn't really matter why, what we dealing with now is what we are confronted with so that was how I sort of deal with that sort of information, but the other people having that burden of the responsibility or feel there as though there's a blame thing, you know, it's quite different. But that's something we have to keep in mind in our conversations with patients is that information has different meanings for them than it might for us." (Focus Group, 2015, p. 21)

Feelings of being inadequately equipped

During the conversation it was clear that there was a recurring theme of nurses not being equipped, trained or provided with adequate education on genetics. This idea bridged between the role of the nurse as described by three participants where the role of the nurse is 'interpreter', support person or information provider;

> "Because I remember in those situations when genetics or whichever, the poor patients would often look to the nurse for help which is horrible, I'm standing up here, I don't have enough information to provide and so the nurses looking at the other person thinking, please for God's sake, please actually talk proper English to this person, they're not quite understanding what they're saying" (Focus Group, 2015, p. 24)

> "The mothers were aware and they continued with the pregnancy and as a nurse, for some of us it was really hard to understand why they would ever go ahead with pregnancy, or not go ahead with a pregnancy, and also if they weren't aware, we had a patient with cystic fibrosis, then the time that it took to test the child and then of course the parents, we tested it and he had an older child that was fine and had no idea and as a nurse they don't think, you know, we are not trained in that area, with enough knowledge at times to support families through that." (Focus Group, 2015, p. 10)

> "You see I covered blood groups a long, long time ago but, yeah, I think we do need more education. I mean, we're kept up to date with how to

> handle IV lines and all this, the latest PICs and whatever, but then we're not really kept up to date with the rest of the scientific society where it can easily impinge on our practice because people come to us wanting answers and like you say, you know, we haven't had enough experience and you don't acknowledge to back it up people still want explanations or to be reassured, you know?" (Focus Group, 2015, p. 27)

The overwhelming nature of the increasing demand for knowledge for nurses was clearly articulated by one participant;

> "Because originally neonatal would do the Guthrie testing and that's for all, you know, certain genetic predisposed illnesses and the parents will ask us and as a nurse we're taking the test so we should have that knowledge and they talk about adding more tests to this Guthrie's card; I mean, how much more are they going to keep testing for? and, you know, then there's the parents will know what the risks are, what the chances are and I mean it's totally tested already and we're not trained, you know, the new babies come in, they might let you do the Guthrie's, you've got to do it in this time period and then you just go and do it. We're not actually trained in what is genetic illnesses and what to tell the parents and the test comes back and the parents sometimes are like really shocked because they've got no idea …well…I really need to know about all of this. I mean it's really going to affect their child so I think probably nurses do need more training and that area, maybe in the specific areas that we work in,

> get more training and education, you know, approaches with parents and helping them with …because they, yeah, [the tests are] going to get bigger." (Focus Group, 2015, p. 19)

One participant saw an alternative view to the idea; that nurses are equipped with the knowledge of how to find information. This idea came hand in hand with the concept of the technology challenge faced by nurses- in particular the role of *Dr. Google* in providing patients with health information.

> "As nurses we are to some greater degree equipped especially probably New Grads how to assess information and find information so, you know, if people are talking to me about what they have heard on the internet for example about hepatitis, I will kind of direct, say, just think about who's writing it and, you know, go to medical sites or, you know, national hepatitis organisations, you know, not someone who's trying to sell goji – what's it called? …Yeah, goji berries as a cure for Hep C or, you know, don't go to the chat room which says that you could get it from drinking a glass of water. So I think it's part of one again that, you know, some sort of discussion about where to find information and how to assess it but you know people ring up and say I hear there's this new medication that cures Hep C, you know, where can I – how can I get it, and you have to go through other kind of overarching things like funding and PHARMAC and, you know, all of those issues and it's not just as simple as that. If you going to get it through compassionate access then you have to have less

> than six months to live so you don't want to be in that group." (Focus Group, 2015, p. 26)

Technology; the role of Google

The increasing role of technology was expressed as influencing both the information the nurse accesses as well as the information patients' access. The focus group agreed there were "pro's and con's" (Focus Group, 2015, p. 21) to using technology such as Google and one nurse illustrated how Google is bridging the gap between her expected role and the limitations her lack of formal education in the topic proved;

> "I think you wing it. I think you're not taught, you know, indicated about genetic or I certainly wasn't when I came from England, you're not taught and then you get somewhere a genetic case that you must follow these steps but you don't, the nurses have empathy and they sit there and they listen to the patients and then might go and Google something, or maybe that's just me. So it's sort of verbal. It's like… Yeah, okay, let's see what we can find out today, your past medical history or how you came about, how you got Huntington's or whatever. But you're certainly not equipped. Yeah, we rely on technology too much now, it's not like we're all full of all this knowledge that we're all experts in the field. That's how I feel. I just wing it." (Focus Group, 2015, p. 17)

One participant provided considered input to her experience over her career and the influence of both google and the media;

> "I think patients are now asking more and more questions and difficult questions and I think that's really because of the media and Google but, you know, what they ask now would be completely different to what they asked five or 10 years ago." (Focus Group, 2015, p. 25)

The ethics of knowing

A divergent topic to the focus group data was the thread that ran through the conversation about the ethics of knowing genetic histories or predispositions. It was a topic that divided opinions between the group with some feeling that genetic testing was going too far and "interfering with whether you should have children" while the countering argument was they were "to save lives" (Focus Group, 2015, p. 15). The group agreed that the ethics changed dramatically between risk for colon cancer and Huntington's disease and humor by a participant was used to break the tension.

> "I'm wondering why they're so obsessed and more keen to know all this genetic history because what are they trying to do with it? Are they trying to eliminate all these diseases in the future and make our health system cheaper to run or something, you know, you don't know what drives them." (Focus Group, 2015, p. 15)

> "I think part of the wanting to know is to know what the inevitable is though, like have a genetic test shows that you do have the gene for breast cancer – sorry, colon cancer, only that can make decisions for future screening as well and if you can have colonoscopies at appropriate intervals that can prevent you from what may eventually develop into bowel cancer so I think for me if there was some medical condition I had

> that had a genetic component or a lot of people in my family had something that may or may not have a genetic link, I would like to know that test's still able to assess my risk." (Focus Group, 2015, p. 16)

Summary of Analysis

The focus group data provided four fundamental themes about how Registered Nurses in the New Zealand setting participate in genetic conversations. These themes were the nurse conversation content, the role of the nurse, responsibility and sense of blame and feelings of being inadequately prepared.

The nurse conversation content varied considerably between participants with one demonstrating in-depth knowledge and confidence around a genetic test but quickly assured the group "but only because that's my area" (Focus Group, 2015, p. 7). Other participants articulated ideas of not engaging in the conversations and diverting people towards clinicians or more specialized professionals. Time was a factor cited as to why the conversations were not consciously started. As the conversation went on and the group dynamics bought both professional and personal stories to the fore it quickly became clear that nurses are having genetic conversations *more* often than the participants previously thought. A strong idea that emerged was the concept of nurses using genetic data to put people in a wider context with evidence of consistencies between the way nurses talk about genetics with the holistic ideas as presented by Dr. Gwen Anderson.

The group was careful to articulate what is and what is not the role of the nurse in genetics with emphasis placed on the nurses' role to be more vocal and supportive and to talk with patients since they cannot initiate investigations. Heavy emphasis was placed on communication of genetic concepts by the clinician and the nurse holding the role of interpreter. While some enjoyed the role,

others found it “horrible” especially when they felt they did not have the information or knowledge to be able to fill that role (Focus Group, 2015, p. 24).

Being inadequately prepared was a concept voiced by multiple participants at various stages of the conversation and it ranged from having inadequate training on how to support families and parents going through genetic testing, having discussions around the genetics of blood groups, having inadequate information to answer patients and parents questions and having little to no education about current genetic tests and concepts. This theme was identified as the key theme in the field notes, debrief session and transcript analysis.

The concept of associating genetics with blame was a theme that emerged with two formats; the blame nurses put on themselves for not recognising a situation earlier or pushing for testing, and the blame they felt surrounded test results and the idea that fault-finding created a burden of responsibility.

Threaded throughout the conversation was the idea of ethics, particularly the ethics of knowing genetic histories and predispositions. While the concept split opinions of the group there was a general consensus that the ethics changed dramatically between individual circumstances and the group dynamics used humour to mitigate any tensions and move the conversation back on topic.

CHAPTER FIVE: A NURSING CONTRIBUTION

> "Science has fractionated the individual from the family and has not reunited them in nursing research" (Hayes, 1993, p. 29)

The data generated from the focus group runs congruently with the academic evidence from the literature review of the concepts of nurses, genetics and communication. It is clear that nurses are having genetic conversations and that there is an overwhelming feeling of being underprepared, undereducated and undertrained to face the challenges these present. The assistance and sometimes hindrance of advancing technologies such as Google is providing a bridge between the roles expected of the nurse; to be supporter, interpreter and information provider. However, equally it is technology that patients are accessing to make them informed consumers.

Two things have developed over the course of this dissertation; the analysis and results from this project has demonstrated a need to articulate how and why genetics must be integrated into the nursing knowledge base and that nurses need something tangible to apply to their practice. Together these prompted the development of the FAMILY mnemonic; developed by the ideas of nurses for nurses.

1. Moving the concept of genetics into the body of nursing knowledge

Moving genetics out of a biomedical silo into a nursing space requires genetics to no longer be seen through the nursing lens as a medical test or concept, but to instead recognize it as being a person's "whole everything" (Focus Group, 2015, p. 28). Genetics represents people's family, their past, their current situation, their future potential health status, and the impact on future generations; be it children yet to come or children already born. With genetics encompassing every part of a person's life the concept of genetics becomes more than a positive or negative test but

brings a sense of responsibility. In line with this is how nurses approach genetics; it needs to shift away from the biomedical view which fosters fault-finding toward a modern nursing perspective such as that proposed over a decade ago by Dr. Anderson.

The position of this dissertation is that nurses are an independent profession with its own voice, culture and knowledge. The idea of a separatist approach to nursing knowledge is to see the knowledge as its own entity (Rafferty, 1996). The fundamental idea here is that in raising the consciousness about the topic we can give voice to the otherwise invisible practice already occurring.

This need for this position becomes evident when reviewing the literature particularly around the ideas of the value given to individualism within the biomedical world view and the *just* a nurse concept. One participant here referred to herself as *just* a nurse when replying to the inclusion criteria question. The idea that "critical theory suggests a series of moves- to refuse, to resist, to reject, to disagree, to criticize, to imagine and to think otherwise- by which the critique of culture may bring about change in society" (Dant, 2003, p. 163) is one that resonates with how I intuitively feel about my research topic. A critical social framework has been used previously to inform nursing research in the New Zealand context using focus groups in a qualitative methodology (Ross, 2001). Within the literature a critical social framework has been implied to give nursing practice a view of clients as people, who communicate and experience life, instead of clinical events (Kim & Holter, 1995).

In line with this position, this research calls for immediate changes in the presentation of genetics to nurses and nursing students. There are genetic competencies set for nurses overseas but they are appropriate for their respective workforces, health systems and clients; making transferring them to the New Zealand context a challenge. Competencies designed for specialist

genetic nurses working in the American context would never be able to directly transfer to a New Zealand nurse working in primary health or the hospital setting. As such a specific genetic nursing framework needs to be designed specifically for the nursing workforce of New Zealand with two goals; providing nurses with the confidence to engage in genetic conversations- regardless of their educational preparation, and providing guidance on their role in these conversations.

2. A Contribution to Nursing; the FAMILY mnemonic

A systematic review of nurses knowledge of genetics demonstrated results similar to the focus group results; nurses felt they did not have adequate preparation but were open to genetic specific education (Godino & Skirton, 2012). The following nursing framework is a simple demonstration of a tool nurses could use to guide their genetic conversations. The FAMILY mnemonic has the potential to provide nurses with the confidence to engage with the knowledge; they do *not* need to know *everything*, and to guide them to what their role in the patient journey at that point in time may require. Based on this research analysis and the literature it incorporates the concerns and questions the registered nurses of the focus group presented about their practice concerning genetics and the types of questions they are often faced with. Mnemonics are common in healthcare, for example the PRACTICE mnemonic (prevalence, risk, attitude, communication, testing, investigation, consent, and empowerment) has been published to guide the role of the physician in genetic cultural competence (Reynolds, Kamei, Sundquist, Khanna, Palmer, & Palmer, 2005).

Letter	Expected Ability	
F	Fears	Recognize the fears presented as valid concern for that person at that moment in time.
A	Alternative world views	Ask what it means to them- and what is important? For example how any samples are treated or information is shared.
M	Medications	Consider pharmacogenetics for those with medical history
I	Information	Is the information they, or you, are sharing current? Is any information, resources, services or technology provided credible, accurate, appropriate and current?
L	Linkage	Can you answer any questions about inheritance chance for simple inheritance patterns of sex, autosomal dominant or autosomal recessive? And draw a pedigree using universal symbols for at least three generations?
Y	Why has the topic come up?	Is there area specific tests? Screening? Who/where can referrals be made?

Table 4: Mnemonic Tool FAMILY for application to Registered Nurses Genetic Conversations in the New Zealand context.

F: Fears

Due to the various levels of understanding people have of genetics what they fear is legitimate to them at that point in time and deserves to be recognized. For example, one person might fear finding out the results to a test and what it will do to their relationship with their family, while another person might fear that the information could be used against them.

A: Alternative world views

Alternative world views cannot be assessed by looking at a person; they need to be asked directly what is important to them? For example is it important to them that elders be present at the time of testing or during counselling sessions? How would they like their samples to be treated? An important aspect to know is will samples be sent overseas for processing and/or analysis? This is vital information to be able to share with people who may feel compromised when samples are sent offshore (Port, Arnold, Kerr, Gravish, et al., 2008). This aspect of the mnemonic corresponds with the ANA professional responsibility competency "demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy, and preferred language" (American Nurses Association, 2009, p. 11).

M: Medications

Pharmacogenetics plays a significant role in the responsiveness to drug therapy (Bullock, 2014). This was illustrated clearly by one nurse's experience in the focus group with Hepatitis therapy drugs. Although medication prescription is largely in the domain of the physician at this time, Nurse Practitioners can prescribe and it is anticipated all registered nurses will have a limited prescribing role in the future (Nursing Council of New Zealand, 2014). It was the experience of the conversations a nurse in the focus group was having on a daily basis that illustrated the need for medications to be included in the FAMILY mnemonic. The ability of the nurse to be able to

communicate these concepts is demonstrated by their ability to be able to describe to someone why blood transfusions need to be cross matched; the concept between this, genetic markers and polymorphisms are similar. While the science behind pharmacogenetics can be intimidating it is not an unfair expectation of nurses to be able to accurately discuss the fundamental concepts at a level appropriate to the client.

I: Information

During a conversation information is shared both ways; the nurse shares with the client and the client shares with the nurse. The message consistent throughout the literature is the ever changing knowledge in the genetics and healthcare fields. With this in mind it is important that information is current and accurate. There are four criteria any information, resources, services or technology must meet to qualify as acceptable; it must be credible, accurate, appropriate and current. This comes directly from the ANA professional practice domain competency; "identifies credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies specific to given clients" (American Nurses Association, 2009, p. 12). The Genomic Policy Unit has the corresponding competency "obtain credible, current information about genetics for self, clients and colleagues" (Genomics Policy Unit, 2003, p. 61).

L: Linkage

It was the inaccuracy of the answer to a linkage question that initiated this research. From the focus group it was questions about linkage that were used the most often to demonstrate the conversations nurses are having and the questions they are facing. Therefore it is important that nurses know the basic inheritance principles in order to be able to appropriately answer these questions. Inheritance though is often complicated by other factors and can be disease specific; for example Otopalodigital syndrome is X linked while Cystic fibrosis is inherited in an autosomal

recessive pattern. It is essential that nurses understand the limits of their own understanding and are sure the information they share meets the criteria of 'I' in FAMILY. The ANA has two explicit linkage competencies; "demonstrates ability to elicit a minimum of three generation family health history information [and] constructs a pedigree from collected family history information using standardized symbols and terminology" (American Nurses Association, 2009, pp 11-12)

Y: Why has the topic come up?

Conversations do not start without some aspect of thought from the client. This question was developed after an inpatient from the hospital made contact with me when he saw my recruiting poster in the cafeteria. He was awaiting cancer related surgery and called to tell me about his family history and the events surrounding the births and phenotypes of his grandchildren. I couldn't help but reflect on the immense importance this topic has to people and the influence a conversation can have on someone's life. I encouraged this person to make contact with the genetic services of the hospital but he changed my perspective of my research entirely. The final aspect of FAMILY encourages nurses to look at the person in context; are they already in the genetic referral system or do you need to investigate the appropriateness of a referral further? Are they in a screening program already? If not do they match the criteria? Is there someone you can ask to follow up? Do they need their fears heard and acknowledged? The core competency this aspect draws from is the ability of nurses to make referral, pass information on and to be an advocate for the person.

Moving forward

From the research presented in this dissertation the following actions are proposed to move the ideas presented here into the nursing knowledge base to strengthen the abilities of Registered Nurses in New Zealand:

- Negotiate with District Health Boards' to offer workshops for registered nurses in order to move genetics from the biomedical silo of health and into a nursing framework; reflecting an autonomous nursing body of knowledge.
- Work towards publishing the FAMILY mnemonic to provide nurses with a tool to guide their genetic conversations.
- Write to the New Zealand Nursing Council regarding the development of genetic competencies for Registered Nurses in the New Zealand context.
- Recreate the study by Nicol, 2002 to determine the current level of genetics taught to undergraduate nursing students in New Zealand.
- Write to schools of nursing to incorporate updated and relevant genetic education into both undergraduate and postgraduate nursing curricula.

APPENDICES

Appendix 1

Competencies from American Nurses Association, 2009.

ESSENTIAL COMPETENCIES

Professional Responsibilities

All registered nurses are expected to engage in professional role activities that are consistent with *Nursing: Scope and Standards of Practice* (2004) by the American Nurses Association. In addition, competent nursing practice now requires the incorporation of genetic and genomic knowledge and skills in order to:

- Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients.
- Advocate for clients' access to desired genetic/genomic services and/or resources including support groups.
- Examine competency of practice on a regular basis, identifying areas of strength, as well as areas in which professional development related to genetics and genomics would be beneficial.
- Incorporate genetic and genomic technologies and information into registered nurse practice.
- Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy, and preferred language.
- Advocate for the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action.

Professional Practice Domain

Nursing Assessment: Applying/Integrating Genetic and Genomic Knowledge

The registered nurse:

- Demonstrates an understanding of the relationship of genetics and genomics to health, prevention, screening, diagnostics, prognostics, selection of treatment, and monitoring of treatment effectiveness.
- Demonstrates ability to elicit a minimum of three generation family health history information.
- Constructs a pedigree from collected family history information using standardized symbols and terminology.
- Collects personal, health, and developmental histories that consider genetic, environmental, and genomic influences and risks.
- Conducts comprehensive health and physical assessments which incorporate knowledge about genetic, environmental, and genomic influences and risk factors.
- Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors.
- Assesses clients' knowledge, perceptions, and responses to genetic and genomic information.
- Develops a plan of care that incorporates genetic and genomic assessment information.

Identification

The registered nurse:

- Identifies clients who may benefit from specific genetic and genomic information and/or services based on assessment data.
- Identifies credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies specific to given clients.
- Identifies ethical, ethnic/ancestral, cultural, religious, legal, fiscal, and societal issues related to genetic and genomic information and technologies.
- Defines issues that undermine the rights of all clients for autonomous, informed genetic- and genomic-related decision-making and voluntary action.

Referral Activities

The registered nurse:

- Facilitates referrals for specialized genetic and genomic services for clients as needed.

Provision of Education, Care, and Support

The registered nurse:

- Provides clients with interpretation of selective genetic and genomic information or services.
- Provides clients with credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies that facilitate decision-making.
- Uses health promotion/disease prevention practices that:
- Consider genetic and genomic influences on personal and environmental risk factors.
- Incorporate knowledge of genetic and/or genomic risk factors (e.g., a client with a genetic predisposition for high cholesterol who can benefit from a change in lifestyle that will decrease the likelihood that the genetic risk will be expressed).
- Uses genetic- and genomic-based interventions and information to improve clients' outcomes.
- Collaborates with healthcare providers in providing genetic and genomic health care.
- Collaborates with insurance providers/payers to facilitate reimbursement for genetic and genomic healthcare services.
- Performs interventions/treatments appropriate to clients' genetic and genomic healthcare needs.
- Evaluates impact and effectiveness of genetic and genomic technology, information, interventions, and treatments on clients' outcome.

From American Nurses Association. (2009). *Essentials of genetic and genomic nursing: Competencies, curricula guidelines, and outcome indicators*. pp. 11-13.

Appendix 2

Competencies designed by Genomics Policy Unit, 2000.

MINIMUM
Each nurse, midwife and health visitor should at a minimum be able to:

Ref.	**Competency**
1	Appreciate limitations of his or her genetic expertise.
2	Understand the social and psychological implications of genetic services.
3	Know how and when to make a referral to a genetics professional.

KNOWLEDGE
All nurses, midwives and health visitors should understand:

14	Basic human genetics terminology
15	The basic patterns of biological inheritance and variation, both within families and within populations
16	How identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options
17	The importance of family history (minimum three generations) in assessing predisposition to disease
18	The role of genetic factors in maintaining health and preventing disease
19	The difference between clinical diagnosis of disease and identification of genetic predisposition to disease (genetic variation is not strictly correlated with disease manifestation)
20	The role of behavioural, social, and environmental factors (lifestyle, socioeconomic factors, pollutants, etc.) to modify or influence genetics in the manifestation of disease
21	The influence of ethnoculture and economics in the prevalence and diagnosis of genetic disease
22	The influence of ethnicity, culture, related health beliefs and economics in the clients' ability to use genetic information and services
23	The potential physical and/or psychosocial benefits, limitations and risks of genetic information for individuals, family members, and communities
24	The range of genetic approaches to treatment of disease (prevention, pharmacogenomics/prescription of drugs to match individual genetic profiles, gene-based drugs, gene therapy)
25	The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities
26	The components of the genetic-counselling process and the indications for referral to genetic specialists
27	The indications for genetic testing and/or gene-based interventions
28	The ethical, legal and social issues related to genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)
29	The history of misuse of human genetic information (eugenics)
30	One's own professional role in the referral to genetics services, or provision, follow-up, and quality review of genetic services

SKILLS
All nurses, midwives and health visitors should be able to:

31	Gather genetic family-history information, including an appropriate (3 generations) family history
32	Identify clients who would benefit from genetic services

33	Explain basic concepts of probability and disease susceptibility and the influence of genetic factors in maintenance of health and development of disease
34	Seek assistance from and refer to appropriate genetics experts and peer support resources
35	Obtain credible, current information about genetics, for self, clients and colleagues
36	Use effectively new information technologies to obtain current information about genetics
37	Educate others about client-focused policy issues
38	Participate in professional and public education about genetics

ATTITUDES
All nurses, midwives and health visitors should:

4	Recognise that philosophical, theological, cultural and ethical perspectives influence use of genetic information and services
5	Appreciate the sensitivity of genetic information and the need for privacy and confidentiality
6	Recognise the importance of delivering genetic education and counselling fairly, accurately and without coercion or personal bias
7	Appreciate the importance of sensitivity in tailoring information and services to clients' culture, knowledge and language level
8	Seek co-ordination and collaboration with interdisciplinary team of health professionals
9	Speak out on issues that undermine clients' rights to informed decision making and voluntary action
10	Recognise the limitations of their own genetics expertise
11	Demonstrate willingness to update genetics knowledge at frequent intervals
12	Recognise when personal values and beliefs with regard to ethical, social, cultural, religious, and ethnic issues may affect or interfere with care provided to clients
13	Support client-focused policies

Genetic counselling
Skills 39-46 delineate the components of the genetic-counselling process and are expected of all health-care professionals who provide genetic counselling services to their clients. However, health professionals should be able to facilitate the genetic-counselling process and prepare clients and families for what to expect, communicate relevant information to the genetics team, and follow up with the client after genetics services have been provided.

39	*Educate clients about availability of genetic testing and/or treatment for conditions seen frequently in practice*
40	*Provide appropriate information about the potential risks, benefits, and limitations of genetic testing*
41	*Provide clients with an appropriate informed consent process to facilitate decision making related to genetic testing*
42	*Provide, and encourage use of, culturally appropriate, user-friendly resources to convey information about genetic concepts*
43	*Educate clients about the range of emotional effects they and/or family members may experience as a result of receiving genetic information*
44	*Explain potential physical and psychosocial benefits and limitations of gene-based therapeutics for clients*
45	*Safeguard privacy and confidentiality of genetic information of clients to the extent possible*
46	*Inform clients of potential limitations to maintaining privacy and confidentiality of genetic information*

From Genomics Policy Unit. (2003). Fit for practice in the genetics era: defining what nurses, midwives and health visitors should know and be able to do in relation to genetics: Report compiled by the Genomics Policy Unit, University of Glamorgan, and Medical Genetics Service for Wales, University Hospital of Wales. pp 61-62

Appendix 3

CINAHL			OVID Medline			Joanna Briggs Database		
#	Search term	Results	#	Search term	Results	#	Search term	Results
S9	((MH "Nurse-Patient Relations")) AND (S1 AND S8)	37	1	exp Genetics/	184174	1	Genetic communication	0
S8	(MH "Nurse-Patient Relations")	18,758	2	Nursing/	49194	2	(genetic 70it e70lling or genetic counselling	4
S7	nurs*	597,570	3	Communication/	63981	3	nurs*	2580
S6	communication	72,236	4	1 and 2 and 3	0	4	genetic*	156
S5	genetic concepts	64	5	1 and 3	379	5	3 and 4	82
S4	("nurse patient relationship") AND (S1 AND S3)	3	6	Nurses/	29877	6	nurse patient relationship	8
S3	"nurse patient relationship"	544	7	5 and 6	1	7	communication	748
S2	((MH "Genetic Counseling") OR (MH "Genetic Counseling (Iowa NIC)") OR (MH "Genetic Diseases, X-Linked") OR (MH "Genetic Markers") OR (MH "Genetic Techniques") OR "genetic") AND nurs*	2,132	8	New Zealand/	30340	8	6 or 7	750
S1	(MH "Genetic Counseling") OR (MH "Genetic Counseling (Iowa NIC)") OR (MH "Genetic Diseases, X-Linked") OR (MH "Genetic Markers") OR (MH "Genetic Techniques") OR "genetic"	49,638	9	1 and 2	61	9	5 and 8	24
			10	8 and 9	0			
S8	S3 AND S7	214	11	8 and 9	0			
S7	S4 OR S5 OR S6	291,073	12	Australia/ or Australasia/ or Adult/	4081279			
S6	(MH "Patient Education")	39,453	13	9 and 12	1			
S5	TI nurs*	244,904	14	3 and 9	0			
S4	(MH "Nurse-Patient Relations")	18,758						
S3	S1 OR S2	2,334	1	Genetics/	11976			
S2	TI genetic 70it e70lling OR genetic counselling	601	2	New Zealand/ or Maori.mp.	30682			
S1	(MH "Genetic Counseling")	2,278	3	1 and 2	7			

S6	((genetic* OR genetic 71it e71lling OR genetic counselling) AND (S2 AND S3 AND S4)) AND (S1 AND S2 AND S3 AND S4)	2	1	(Genetic 71it e71lling or genetic counselling).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	19416
S5	(genetic* OR genetic 71it e71lling OR genetic counselling) AND (S2 AND S3 AND S4)	13	2	Nurses/ or "Attitude of Health Personnel"/	119855
S4	genetic* OR genetic 71it e71lling OR genetic counselling	57,249	3	1 and 2	253
S3	Maori OR New Zealand OR Indigenous population	17,806	4	Health Communication/ or Nonverbal Communication/ or Communication/ or Persuasive Communication/ or Communication Barriers/	74870
S2	communication OR nurse patient relationship OR attitude*	219,148	5	3 and 4	19
S1	nurs*	597,570	6	Genetics/ or Genetics, Medical/ or Genetics, Behavioral/ or Genetics, Population/	53602
			7	2 and 4 and 6	7

Appendix 4

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Ref: HEC 2015/72/LR

2 September 2015

Chloe Ward-Smith

School of Health Sciences

UNIVERSITY OF CANTERBURY

Dear Chloe

Thank you for forwarding your Human Ethics Committee Low Risk application for your research proposal "How do registered nurses in the New Zealand setting participate in genetic conversations? An exploratory study".

I am pleased to advise that the application has been reviewed and approved.

With best wishes for your project.

Yours sincerely

Lindsey MacDonald

Chair, Human Ethics Committee

Appendix 5

RESEARCH OFFICE TO FACILITATE APPROVAL FROM CDHB GENERAL MANAGER/S

General Manager sign-off

This research will take place in your hospital, do you approve it?

Hospital 1	Pauline Clark General Manager Christchurch Hospital *Name:*	Pauline Clark *Signature:*	30/9/15. *Date:*
Hospital 2	*Name:*	*Signature:*	*Date:*
Hospital 3	*Name:*	*Signature:*	*Date:*

Appendix 6

RE: Recruiting RN's to participate in focus group

From: **Stu Bigwood** (Stu.Bigwood@cdhb.health.nz)
Sent: Thursday, 29 October 2015 6:08:34 p.m.
To: 'Chloe Louise' (chloelou@windowslive.com)

Hi Chloe,

I am pleased to confirm our local research CTTEE has approved your project.

Please feel free to contact me if you require anything further

Regards

Stu

Stu Bigwood

Director of Nursing

Specialist Mental Health Service

Canterbury district Health Board

Avon Admin Building 6

Hillmorton Hospital

Appendix 7

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2015/72/LR

29 October 2015

Chloe Ward-Smith

School of Health Sciences

UNIVERSITY OF CANTERBURY

Dear Chloe

Thank you for your request for an amendment to your research proposal "How do registered nurses in the New Zealand setting participate in genetic conversations? An exploratory study" as outlined in an email from your supervisor, Alison Dixon, dated 28 October 2015.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Please note that this approval is subject to the following:

- In the advertisement, please include a note to the effect that this research has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Yours sincerely

Lindsey MacDonald

Chair, Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. **www.canterbury.ac.nz**

F

E S

Appendix 8

RE: Maori consultation for Research Project

From: **Catherine Grant** (Catherine.Grant@cdhb.health.nz)

Sent: Wednesday, 30 September 2015 11:50:39 a.m.

To: 'Chloe Louise' (chloelou@windowslive.com)

Thank you for your email regarding fast tracking your research project.

We are committed to providing a good and fair consultation process and always try to make this as straight forward as possible. However it should be noted that review of research studies is done by our busy kaimahi, whose primary role is to provide support to patients/whanau and staff in the hospital setting. We rely on their continued good will in reviewing these studies and our present process provides them the necessary time to do so.

While we can "fast track" studies, this is not the preferred course of action and unfortunately these requests seem to be increasing. I know that the CDHB Research Office is working with both CPIT and the University of Canterbury in making everyone aware of what is required.

I have discussed your request with Eru Waiti, Team Leader and Chair of Te komiti Whakarite, and he is happy for you to proceed with your study while we undertake our review.

You should be aware that as an Iwi authority Ngai Tahu has made the statement that they do not wish to have their genetic lines studied and that Maoridom, as a whole, have grave concerns around the cultural safety of the collection and study of genetics. We are mostly likely to expand on this once the review process has been undertaken and you might be asked to acknowledge these concerns in you research.

If you have any question about this, please feel free to contact me or Eru Waiti.

Ngā mihi

Catherine

Appendix 9

30th October 2015

Chloe Ward-Smith

University of Canterbury

Re: How do Registered Nurses in the New Zealand Setting Participate in Genetic Conversations; an exploratory study.

Tena koe Chloe,

Ka nui te mihi tenei ki a koe me tou roopu o nga Kairapukorero ki te hapai o te kaupapa whakahirahira mou, moku mo tatou katoa. Ko Rapunga Korero te mea nui. No reira tena koe me te roopu o ka Kairangahau, tena koutou katoa.

Thank you for submitting your research for assessment by Te Komiti Whakarite. I note that your research is an exploratory study involving a small focus group of registered nurses and as such it is always challenging to make comment in terms of achievement for improving Māori Health status.

It is a requirement of the ethics approval process that a final report be submitted when the research is complete. A copy of the report should be provided to me at that time. Te Komiti Whakarite would be willing to assist in the dissemination of your findings once your project has reached a successful conclusion to the appropriate Māori organisations, Māori health professionals and Māori researchers.

We do not intend to hinder the ethics approval process and therefore we do not require a response as the final decision is with the Ethics Committee.

Heoi ano

Eru Waiti
Chairperson
Te Komiti Whakarite

Appendix 10

RE: For the Attention of Ms Gordon: Research within CDHB including nurses

From: **Sue Imrie** (Sue.Imrie@cdhb.health.nz)
Sent: Tuesday, 29 September 2015 2:56:56 p.m.
To: 'Chloe Louise' (chloelou@windowslive.com)
Cc: 'Alison Dixon' (Alison.Dixon@cpit.ac.nz); Heather Gray (Director of Nursing) (Heather.Gray@cdhb.health.nz)

Hi Chloe

I have discussed with Mary Gordon your request, and also Alison's separate email regarding your research project.

Mary is happy to approve your project.

I have cc Heather Gray, Director of Nursing – Christchurch Hospital so she is aware of your pending research.

Kind regards

Sue

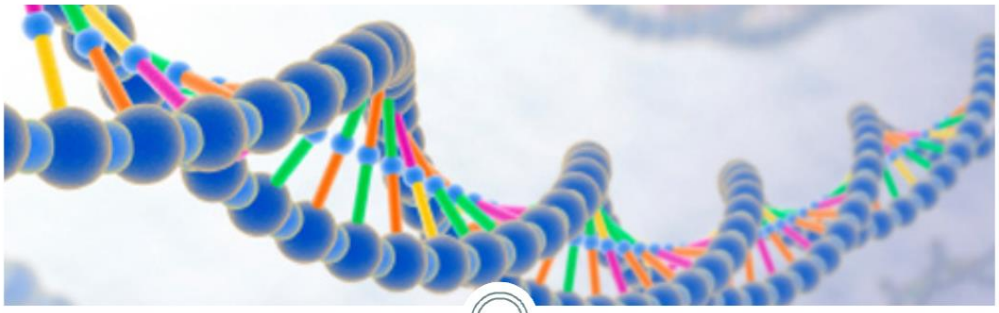
Sue Imrie

Personal Assistant to Executive Director of Nursing

& Executive Director of Māori & Pacific Health
Canterbury District Health Board | PO Box 1600 | Christchurch 8140

Appendix 11

First Recruitment Poster



How Do We Talk About Genetics?

Hi! My name is Chloe Ward-Smith and I am currently undertaking my Masters of Health Science.

As part of my research I am looking at how New Zealand Registered Nurses respond to, initiate, communicate, or interact in situations where the concept topic or ideas about genetics arise.

So what's involved? A small focus group will meet for 90 minutes to discuss the topic in a conference room of Christchurch Public Hospital between 3.30pm and 5pm (after the morning shift).

Who do I require? Registered Nurses (NZNO pay scale SN1 to SN5)

What's in it for you? Afternoon tea with food will be provided.

If this sounds like something that interests you, or have any questions, please don't hesitate to contact me using the details below.

Thank you!

Chloe Ward-Smith BBioMedSci(Hon)

Phone: 0278296702
(03) 3476714 c
chloelou@windowslive.com

Chloe
Phone: 0278296702
(03) 3476714 c
chloelou@windowslive.com

Appendix 12

Second Recruitment Poster

Appendix 13

Information Sheet for Participants

This research is part of a Masters of Health Sciences articulated with Bachelor of Nursing programme. Based on the question "how do New Zealand nurses participate in genetic conversations?" The aim of the research is to explore how registered nurses respond to, initiate, communicate, or interact in situations where the concept, topic, or ideas about genetics arise in their nursing practice. To explore this question it is intended to run a small focus group of six to 10 registered nurses to discuss the topic.

Your involvement in this project will be attending a focus group which will be ran on a day that is convenient to a minimum of 6 participants. It is anticipated it will take approximately 90 minutes of your time, if an afternoon is most suitable it will run from 3.30pm to 5pm. The time and place will be negotiated with the participants.
The focus group discussion will be audio recorded. Present at the group will be myself, the principal researcher, and a second person, a research assistant, who is not participating in the group but who will ensure the recorder is working, offer afternoon tea and take notes.

As a follow-up to the focus group discussion, you will receive a copy of the transcribed group discussion. There will be no identifying factors in this transcript. You will have the opportunity to review the transcript in order to review the group discussion; not individual contributions, and make any amendments. You will be required to return your copy of the transcript to the researcher after two weeks (postage will be included).

There is potentially a very low risk of offence to individuals or identification of practice experiences that may cause distress. In the event that the situation arises that any member of the group feels they need additional support professional independent counsellors will be available.

You will receive a copy of the project results at the conclusion of the project.

Participation is voluntary and you have the right to withdraw at any stage without penalty. There will be no identifying factors of members of the focus group which means you cannot withdraw your individual contribution to the group discussion

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public without your prior consent. To ensure anonymity and confidentiality, the research assistant and the transcriber will be required to sign confidentiality agreements and any identifying factors will be removed from transcripts. All data will be stored securely and only the researcher will have access to this data. This project will be published as a thesis. A thesis is a public document and will be available through the UC Library.

The project is being carried out by Chloe Ward-Smith under the supervision of Dr. Alison Dixon, who can be contacted at alison.dixon@canterbury.ac.nz. She will be pleased to discuss any concerns you may have about participation in the project.

HOW REGISTERED NURSES IN THE NEW ZEALAND SETTING PARTICIPATE IN GENETIC CONVERSATIONS

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return by the return envelope provided to Chloe Ward-Smith.

Chloe Ward-Smith ***BBioMedSci(Hon)***

Appendix 14

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

How do Registered Nurses in the New Zealand setting participate in Genetic Conversations

Consent Form for Participants

I have been given a full explanation of this project and have had the opportunity to ask questions.
I understand what is required of me if I agree to take part in the research.
I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable. I understand that I cannot withdraw my individual contribution to the group discussion.

I understand that any information or opinions I provide will be kept confidential to the researcher, research assistant, transcriber, and other members of the focus group and that any published or reported results will not identify the participants or place of work. I understand that I am required to maintain the confidentiality of other members of the focus group and of the contents of the focus group discussion. I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

I understand that I can contact the researcher Chloe Ward-Smith, chloelou@windowslive.com, or supervisor Dr. Alison Dixon, alison.dixon@canterbury.ac.nz, for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (humanethics@canterbury.ac.nz)

By signing below, I agree to participate in this research project.
Signed:
Date:
Please return this signed consent form to Chloe Ward-Smith by the paid postage envelope provided.
Chloe Ward-Smith ***BBioMedSci(Hon)***

Appendix 15

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

How do Registered Nurses in the New Zealand setting participate in Genetic Conversations

Ground Rules for Focus Group Discussion

These Ground Rules will be confirmed at the start of the focus group and modified if necessary.

- All participants contributions are valid
- There are no right or wrong answers, each participant's contribution is valid.
- All participants to be encouraged by the group to contribute to dialogue.
- Only one person to speak at a time.
- No side conversations amongst other group members whilst one person is speaking
- Identify self as a 'new speaker' for recording purposes (do not use your name or other identifying factor).
- Confidentiality and anonymity of focus group members and dialogue not to be discussed with any third party; all discussions to remain within the room.
- Meeting to start and finish on time.

Appendix 16

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

How do Registered Nurses in the New Zealand setting participate in Genetic Conversations

Inclusion Criteria Form

Please indicate your role as a Registered Nurse on this form and return it to Chloe Ward-Smith, 7 Russell Road, Burnham, 7600 in the envelope provided with the signed consent form if you wish to continue to be involved in this project.
These details will be kept confidential and securely stored with the researcher. The reason behind collecting this information is to ensure the members of the focus group are not put at risk by having power relationship imbalances within a group. Please circle that most applicable to you. If applicable circle more than one. Feel free to add comments.

Nurse Manager

Unit Nurse Manager

Clinical Educators

Specialist

SN5

SN4

SN3

SN2

SN1

Other (please describe)

Appendix 17

Preliminary questions developed for focus group to initiate dialogue

1. **What do you consider a 'genetic conversation' to be?**

- Justification: Designed to be first question in order to establish what the group defines the topic to be from the outset. Does not ask for personal reflection, attitude or behavior; thus acts as a functional 'ice breaker' by encouraging participation without asking for input some may feel will leave them exposed to judgement.

2. **How do you react when the topic of 'genetics' arises?**

- Justification: Question is open ended with clear, simple language. Begins internal reflection by participants of their behaviors and attitudes around the topic in a non-threatening manner. Aims to encourage participants to put forward suggestions in the hope it will establish a common ground from which participants will begin to trust the group and feel it is a safe environment in which they can participate.

3. **How do you feel about discussing genetics regarding Maori and Maori culture**?

- Justification: Potentially the most sensitive question as it directly asks about culture and this research is bound by the treaty of Waitangi to reflect its principles. It would be unjust to not include a question that directly asks people about Maori and genetics. This question developed from anecdotal evidence of 'fear' in people (nurses and nursing students) to broach the topic. Questions aims to illustrate potential reasons for this. Question is designed to include Maori people, culture and customs in research; essential if this research is to situate itself in the New Zealand setting.

4. **How would you describe your 'nursing' participation in these conversations?**

- Justification: Question directly reflects research question. Designed as third question in order to have established group and individual ideas around the fundamental topics.
- Potential need to define 'nursing participation' as it is not a clear term: defined as 'how you, as a nurse, respond to, initiate, communicate, or interact in situations where the concept, topic, or ideas about genetics arise.

5. **Are there any experiences you would be willing to share regarding genetics and your nursing?**

- Justification: Question designed to bring evidence and illustration to the conversation to support ideas and concepts discussed.

Appendix 18

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

How do Registered Nurses in the New Zealand setting participate in Genetic Conversations
Confidentiality Agreement for Research Assistant

I understand that by witnessing, assisting in the running of, and taking notes of, the focus group about the above topic I will become privy to the identity, opinions, and experiences of others.

By signing this form I agree to keep all aspects of my experience in this research confidential. This includes all aspects of group member's identity, their opinions and anything they choose to share with the group or the researcher.

By signing this form I agree to keep the contents of the discussion, the field notes I take, and members' identifying factors confidential.

I understand that I can contact the researcher Chloe Ward-Smith, chloelou@windowslive.com, or supervisor Dr. Alison Dixon, alison.dixon@canterbury.ac.nz, for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (humanethics@canterbury.ac.nz)

Name Eleanor Stronach

Signature [signature]

Date 6/11/2015

Please return this confidentiality agreement form to Chloe Ward-Smith, researcher, prior to the beginning of the focus group.

Chloe Ward-Smith ***BBioMedSci(Hon)***

Appendix 19

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

How do Registered Nurses in the New Zealand setting participate in Genetic Conversations
Confidentiality Agreement for Transcriber

I understand that by transcribing this audio file of a group discussion about the above topic I will become privy to the opinions, and experiences and potentially the identity of the group member.

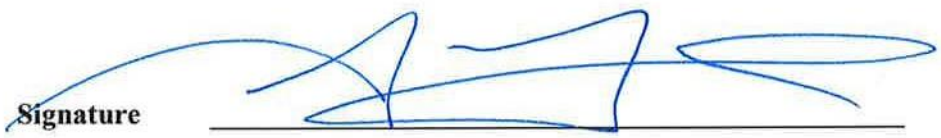
By signing this form I agree to keep all aspects of what I hear and write confidential. This includes all aspects of group member's identity, their opinions and anything they choose to share with the group or the researcher.

I understand that I can contact the researcher Chloe Ward-Smith, chloelou@windowslive.com, or her supervisor Dr. Alison Dixon, who can be contacted at alison.dixon@canterbury.ac.nz for further information.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and I should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

Name Timothy Fine

Timothy Fine (for an on behalf of the company, Adept Secretarial and Training Services Limited)

Signature 

Date 17/11/15

Please return this confidentiality agreement form to Chloe Ward-Smith prior to beginning transcribing/listening to audio file.

Chloe Ward-Smith ***BBioMedSci(Hon)***

Appendix 20

Department: School of Health Sciences
Telephone: +64 03 347 6714 / 027 829 6702 Email: chloelou@windowslive.com
20/08/2015

Kia Ora Everyone,

Please find enclosed the transcript from our focus group held on the 6th November. The transcript has been transcribed by a third party, I have already gone through it myself with the audio to make sure it matches as close as possible but there are still some places where the audio is not clear enough to make out the precise wording so I have left it as 'INDISTINCT (time)' because the last thing I want to do is put words in your mouth.

Feel free to add to it, draw on it, take bits out, adjust bits as you see fit. The purpose of sending it out to you all is to give you the opportunity to decide if you feel the transcript gives an accurate recount of the conversation we had that day. We have coded the transcript as 'P' for any participant and 'F' for myself, the facilitator. This means that we cannot withdraw any data from any individuals from this point on- but if you wish to leave the project you can do so without any penalty.

Once you have read through this and adjusted it please send it back to me in the envelope provided to :

Chloe Ward-Smith

7 Russell Road

Burnham 7600

On receiving the transcript you have 10 working days to review it before it needs to be posted back to me. Once returned I will send the certificates and letters for your PDRP and competencies evidence to you.

Thank you again for being involved in this project- the work that will come out of this would never have existed had it not been for you all, your opinions and your thoughts.

Kind Regards

Chloe

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